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What are parents' experiences of caring for their children with epilepsy? A qualitative systematic review and thematic synthesis, and;

Mothers' experiences of being told about the risk of sudden unexpected death in epilepsy (SUDEP) for their child: An Interpretative Phenomenological Analysis.

Helen Galliard



THE UNIVERSITY
of **EDINBURGH**

Doctorate in Clinical Psychology
The University of Edinburgh
June 2018

Declaration of Own Work

Name: Helen Galliard

Title of Work: 'What are parents' experiences of caring for their children with epilepsy? A systematic review and thematic synthesis', and 'Mothers' experiences of being told about the risk of sudden death in epilepsy (SUDEP): An Interpretative Phenomenological Analysis'.

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Date

Acknowledgements

Firstly, I want to sincerely thank the mothers who gave up their valuable time to participate in the project, I was inspired by hearing about your love for your children and I hope I have done a reasonable job of representing your experiences.

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CHAPTER 1: THESIS PORTFOLIO ABSTRACTS

Systematic Review Abstract

Background: Parents of children with epilepsy have been shown to have higher rates of depression, anxiety and stress in comparison to parents of children without epilepsy due to the impact of caring for a child with a chronic condition. A systematic review of existing literature aimed to identify qualitative research that examined parents' experiences of caring for their children with epilepsy.

Methods: The systematic review explored the experiences that parents have in caring for their child with epilepsy. A search of electronic databases for qualitative literature was completed. The quality of all eligible articles papers was assessed, and findings from studies were synthesised.

Results: Twelve studies met inclusion criteria for the review; findings suggest that parents need time to process their child's diagnosis of epilepsy; they cope with this in differing ways and are motivated to learn how to adapt and cope with parenting their child with epilepsy.

Conclusions: Parents of children with epilepsy may experience symptoms of stress, this may motivate them to learn how best to care for their child.

Empirical Paper Abstract

Background: Parents' experiences of being told about sudden unexpected death in epilepsy (SUDEP) may be particularly challenging to cope with. As little is known about how mothers understand and make sense of SUDEP, a qualitative research project aimed to explore mothers' experiences. It was hoped this would be helpful for clinicians to understand in order to assist them in providing information to parents in a way that minimises distress.

Methods: The empirical article explored mother's experiences of being told about SUDEP and the subsequent impact of this for 11 mothers of children with epilepsy. Interpretative Phenomenological Analysis methodology was utilised, with themes derived from interpretation of interview transcripts, in order to describe the experiences of the participants.

Results: Within the empirical study, five themes emerged. The way in which mothers found out about SUDEP seemed to have a link to their perception of risk and how they subsequently managed feelings of uncertainty and the psychological impact of knowing about SUDEP. Mothers' recommendations to clinicians included when, how and what to tell other parents, and were based on their own helpful and unhelpful experiences of being informed about SUDEP.

Conclusions: In being told about SUDEP, mothers may struggle to make sense of it and this can be associated with an increase in anxiety. However, clinicians can reduce potential distress by carefully timing when and how they tell parents, and by making sure information is clear and relevant for the child in question.

Thesis Portfolio Lay Summary

Parents of children with epilepsy have been shown to have higher rates of depression, anxiety and stress due to the impact of caring for their children. A review of research aimed to understand parents' experiences in detail.

The review explored the experiences of parents caring for their child with epilepsy. An electronic review of qualitative literature was completed. Qualitative research looks closely at people's experiences, often by interviewing them, instead of using quantitative information, which involves using numbers and statistics. The quality of articles was considered, and themes within the findings were discussed. Twelve studies were included in the review. The findings suggest that parents need time to process their child's diagnosis of epilepsy and that they cope with this in differing ways. For example, some parents do not report experiencing ongoing anxiety symptoms, perhaps due to their use of adaptive strategies (for example: reappraisal, distancing, humour, accessing support from others etc.), whereas others may use strategies that maintain anxiety (for example: worry, the suppression of emotions or behavioural avoidance of anticipated challenging situations etc.). Parents also reported being motivated to learn how to care for and parent their child with epilepsy.

Parents' experiences of being told about sudden unexpected death in epilepsy (SUDEP) may be particularly difficult. SUDEP is a death that is

sudden and unexpected, and can happen with or without a seizure having occurred. However, little is known about how parents understand and make sense of SUDEP. This is important for professionals to understand so they can reduce parents' stress where possible.

To explore this issue, a research article explored the views of 11 mothers being told about SUDEP. This was done by interviewing the mothers and asking what the impact was on them and their family members. They were also asked how they would like professionals (such as doctors or nurses) to tell them about SUDEP.

Within the completed interview study, five overarching themes were seen. The way parents found out about SUDEP seemed to link to their understanding of how likely SUDEP was for their child and how they coped with knowing about SUDEP. Parents recommended that professionals tell parents about SUDEP as soon as possible, use understandable language and make the information specific to their child.

CHAPTER 2: SYSTEMATIC REVIEW JOURNAL ARTICLE

What are parents' experiences of caring for their children with epilepsy? A qualitative systematic review and thematic synthesis.

Written in accordance with author guidelines for:

Seizure (See Appendix A).

Abbreviated title for running head:

Parents' experiences of having a child with epilepsy: a review.

Keywords:

Parents

Epilepsy

Children

Experience

Qualitative research

Systematic Review Abstract

Background

Parents of children with epilepsy have been shown to have higher rates of mental health difficulties. This may be due to the impact of caring for a child with a chronic condition. Qualitative research focuses on how people make sense of the world and how they experience events. A previous review of qualitative literature focused on the research of children with epilepsy alongside their siblings and parents, focusing on who was included in such studies, methodological concerns regarding research with children and to identify common themes across all relevant studies. The present review aimed to identify qualitative literature that explores issues specifically related to parent's experiences of caring for their children with epilepsy.

Aims

To carry out a systematic review and synthesis of qualitative research to answer the question: 'What are the experiences of parents who have a child with epilepsy?'.

Methods

A search of electronic databases ASSIA, CINAHL, Medline, PsychInfo and Embase was conducted for qualitative research published in the English language between 1970 and 2017. Articles were included if they comprised primary research, used a qualitative methodology (or mixed methods that

included qualitative methodology), participants were parents or caregivers of children (aged 18 and under) with epilepsy and included the experience of parenting a child with paediatric epilepsy. Twelve studies were identified as eligible for inclusion in the review. These were rated for quality using the Critical Appraisal Skills Programme (CASP) tool. Thematic synthesis was used to analyse the data.

Results

Overall, the quality of eight articles was rated as being of a medium risk of bias with most relevant areas adequately addressed. Two articles were rated as being at a higher and two at a lower risk of bias. Data from the identified studies were analysed and thematically synthesised with five themes being identified: time to process the diagnosis, the impact of epilepsy, information (sources, content), relationships with professionals / healthcare systems and role changes.

Conclusion

Qualitative research has provided unique insights into experiences of the parents of children with epilepsy. From the data synthesis, findings suggest that parents need time to process their child's diagnosis, cope with this in differing ways and are motivated to learn how to adapt their parenting in order to support their child with epilepsy. It is important for clinicians in this field to understand the experiences of parents in order to provide effective support.

Introduction

The impact of childhood epilepsy on families can be significant. Although some children may have no symptoms aside from episodes of seizure, others may have widespread cognitive and/or physical difficulties. For children with epilepsy, issues can be related to physical, cognitive, behavioural and psychological functioning [1]. Regarding the physical impact of epilepsy, children may experience headaches, muscle weakness, fatigue following a seizure and a related need for increased sleep as well as sleep difficulties [2,3]. Children may experience cognitive difficulties including memory impairment, attention deficits and a reduced speed of information processing as a consequence of an interrelation between the underlying aetiology of epilepsy, seizures themselves and due to the side effects of anti-epileptic medication [4,5]. Behavioural disorders including hyperactivity, aggression and conduct difficulties have been found to be approximately five times higher in children with epilepsy compared with those without [6,7] and are usually considered to be multi-aetiological [8]. Regarding the psychological impact of epilepsy, an epidemiological study showed that the rate of psychiatric disorders in children with epilepsy was 37% [9], with anxiety and depression found to be the most common difficulties [10,11], and research also highlights an increased risk of suicidal ideation and suicide attempts [12].

Epilepsy can arise from an underlying neurological condition that causes seizures and which may also give rise to behavioural problems; these may coexist rather than epilepsy causing behavioural difficulties. However, there

will be psychological / cognitive effects from the seizures themselves for some children and this is where epilepsy itself is relevant. It may be difficult to disentangle these issues as a child develops.

Research has demonstrated that parents and caregivers of children with epilepsy are affected in terms of their psychological functioning, and have been found to experience higher rates of depression, anxiety and stress [13,14] than parents of children without epilepsy. In a systematic review of quantitative research, Ferro and Speechley [18] found that up to 50% of mothers of children with epilepsy were at risk from clinical depression, although they argued there was a need for more methodologically robust research to understand specifically why this was the case.

It is difficult to determine linkages between variables within such a complex area, and much of the existing research looks generally at determining if parents experience anxiety, depression or other mental health difficulties, rather than looking more specifically at the 'why?' of this.. It may be that existing studies began with preconceptions regarding the difficulties that parents may experience; for example using apriori hypotheses about the psychological impact and using psychiatric diagnoses to categorise psychological outcomes when the underlying relationships may be more complex, or the effects not meet diagnostic thresholds. For example, Li et al. [25] used the Short-Form Health Survey (SF-36), Zung Depression Scale (ZDS) and Zung Anxiety Scale (ZAS) to compare parents with a child who has epilepsy and parents who have a child without epilepsy, finding that those who had a child with epilepsy had significantly higher levels of anxiety

and depression than those who had a healthy child. In their discussion, Li et al. suggest possible reasons for this, including stigma and resulting isolation. They also reference their initial clinical assumption that parents of children with epilepsy would thus be found to have higher anxiety and depression scores overall.

Additionally, there are comorbidities with epilepsy (for example, there is a high rate of comorbidity such as intellectual disability [1]), and accordingly it is difficult to separate out what may affect parental well-being – and in what proportion: be it the epilepsy itself or a comorbid condition. Also, epilepsy in and of itself is a highly heterogeneous condition, and therefore challenges to caregivers will vary depending on the seizures experienced by the child and the degree of control that it is possible to reach with these.

Relatedly, in a recent systematic review of quantitative research, Jones and Reilly [19] aimed to determine the prevalence of anxiety in parents of children with epilepsy and identify factors related to this. They found that symptoms of anxiety were common in parents of children with epilepsy, but could not identify a consistent pattern in relation to factors associated with anxiety due to a lack of longitudinal data on the trajectory of anxiety symptoms.

A limited number of studies have found that parental anxiety that focuses on effectively managing seizures, but not general anxiety, decreases over time [20]. This may suggest that as parents become more familiar with their child's seizure disorder their anxiety decreases. However, due to the varying

characteristics of children's seizure disorders and the measures used across data, it is difficult to identify any overall patterns within the data [19].

It has been suggested that the care requirements of children with more severe seizure disorders are associated with a larger burden of day-to-day care. Thus, parents of more severely affected children may be at greater risk of anxiety in general (due to potential stress of this day-to-day care burden), in comparison to parents of children who have fewer, or less severe, seizures. However, it is important to differentiate between the potential impact of a seizure disorder and the effect of a co-morbid condition; given, for example, that degree of intellectual disability is positively correlated with severity of seizure disorder [21].

Limited research in this area suggests that the relationship between parental emotional adjustment and seizure variables is not well understood with inconsistency in findings across studies. Kerne and Chapieski [22] found that seizure frequency was not associated with scores on the Parental Anxiety about Epilepsy questionnaire [17], although they did find that having a child who took a greater number of anti-epileptic medications and had a higher number of secondary generalised seizures did correlate to higher scores on the questionnaire. Conversely, Yong et al. [23] found that parental anxiety as measured using the Hospital Anxiety and Depression Scale [24] was correlated with seizure frequency, but the age of receiving an epilepsy diagnosis, duration of epilepsy, number of anti-epileptic medications or seizure type were found to be significantly associated with parental anxiety. Importantly, seizure severity is typically understood not just by the number of

seizures, but seizure type, the number of medications, and whether or not a child is symptomatic. Although, as Kerne and Chapieski found that the greater number of anti-epileptic medications was correlated to higher parental anxiety and Yong et al. found frequency as predictive, they found different relationships between specific variable that are all proxies of severity. Lv et al. [25] also looked at the impact of childhood epilepsy on parental quality of life and psychological health and aimed to investigate possible correlations. They found that parents of children in a poorly controlled epilepsy group had lower quality of life and higher levels of anxiety and depression. They highlighted that there may be many possible reasons for this, including restricted time to spend with family and friends, the potential difficulties in having full time employment when caring for a child with intractable epilepsy and consequent financial implications.

To date, statistical relationships have identified that parents with children with epilepsy are more likely to experience psychological difficulties. Research has highlighted issues related to the demands of parenting a child with epilepsy on a day-to-day basis [15], changes in family relationships as a consequence of the child's disability [16], as well as the severity of the disability and level of functioning of the child [17]. However, at present it has been seen that the factors that may contribute to parents psychological functioning in caring for their child with epilepsy are still to be fully established [26]. To help disentangle the factors that contribute to parental distress, there is an emerging body of qualitative literature that examines the experience of parents using a different methodological stance. Qualitative

research specifically aims to provide a nuanced understanding of experiences rather than quantifying pre-determined variables. Thus, it is well placed to shed light on the way in which parents make sense of their experience of parenting a child with epilepsy. As such, it may give helpful insight into the potentially complex and interlinked contributory factors associated with parental psychological functioning when caring for a child with epilepsy.

Harden et al. [27] set out three aims for their review: (i) to establish who was included when studying family experiences of childhood epilepsy, (ii) to identify methodological shortcomings in research involving children with epilepsy, and (iii) to synthesise findings from qualitative research with families. With regard to the latter aim, Harden et al [27] identified two main themes: normalcy was seen as central to children and parents, with parents highlighting the impact of epilepsy on their caregiving role and personal identity, although the extent of this and ways in which it impacted parents was not addressed.

Secondly, a theme of the agency of children in coping with epilepsy was found. Harden et al. note that within their identified articles, the parent's perspective was neglected. The present review accordingly aimed to systematically review and thematically synthesise qualitative research regarding the parental experience of caring for a child with epilepsy.

Methods

In line with guidelines for completing qualitative systematic reviews [28], the steps included identifying suitable research articles, critically appraising identified articles and synthesising findings.

Search strategy

To develop MeSH (Medical Subject Heading) search terms, the SPIDER (sample, phenomenon of interest, design, evaluation, research type) tool [29] was used. This is specifically designed for qualitative evidence synthesis. The SPIDER strategy also offers a way to search in a standardised way for qualitative material. The final search terms used were: parent* OR mother* OR father* AND epilep* AND interview* OR Experience* OR understand* OR opinion* OR percep* OR belie* OR feel* OR know* OR qualitative.

Electronic databases PsychInfo, Medline, Embase, ASSIA and CINAHL were searched using the search terms on 4th January 2018. Deduplication was included within these searches (see Appendix B). However, as indicated in Tsafnat et al. [30], when automating deduplication it is still possible that duplication occurs depending on the way in which information is included within the database citation information strings. This was therefore also checked for as part of the manual screening process.

Inclusion and exclusion criteria

Research articles were only included if they met the inclusion and exclusion criteria (see Table 1). Articles were required to be primary research published in a peer-reviewed journal. It was considered that published literature was more likely be of higher quality than unpublished, grey literature having been subject to a peer-review process. Grey literature was also considered to be out with the feasible scope of the present review due to the focus on extracting qualitative data. In non-standard formatted grey literature, it is possible that formatting would have made data extraction more time consuming, and therefore was out with the resources available for the present review.

Regarding population, research participants were included if they were parents of children (which was defined as individuals of 18 years-old and under) with epilepsy, aimed to include exploration (at least in part) of parental experiences of living with paediatric epilepsy and that data collection and analysis used a qualitative methodology (or mixed methods that included qualitative methodology).

Table 1: Systematic review article inclusion and exclusion criteria.

	Inclusion Criteria	Exclusion Criteria
Study Design	<ol style="list-style-type: none">1. Published primary research2. Qualitative methodology (or mixed methods including qualitative methodology)	<ol style="list-style-type: none">1. Reviews of the literature2. Quantitative research3. Grey literature
Population	<ol style="list-style-type: none">1. Parents with children (18 and under) with epilepsy	<ol style="list-style-type: none">1. Studies involving children and adults with epilepsy2. Studies involving children with multiple non-neurological physical health conditions.
Study focus	<ol style="list-style-type: none">1. Parents experiences of living with paediatric epilepsy	<ol style="list-style-type: none">1. Specific epilepsy treatments2. Epilepsy surgery
Date	1970 to 2017	Pre-1970
Language	English language papers	Non-English papers

To establish a workable boundary for a time-constrained review, a choice was also made to limit the search to primary research published in English between 1st January 1970 and 1st January 2018. It was assumed that data conducted prior to 1970 would not provide in-depth interpretative data, as most studies to this time had been quantitative in nature. To verify this assumption, a search for data pre-1970 was conducted, and no articles meeting the inclusion criteria were identified (see Appendix C).

Reflexivity

Reflexivity relates to sensitivity to the ways in which the researcher and the research process may shape the data collected. Accordingly, of relevance is that while conducting the review, the primary researcher was conducting qualitative research regarding parents experiences of being told about the risk of SUDEP (sudden unexpected death in epilepsy) for their child. It is possible this may have had an impact on data synthesis in terms of which areas were focused on as important.

In addition, at the time data was extracted and analysed, the primary researcher was a trainee Clinical Psychologist with an interest in long-term health conditions and who has had experience of working with parents with children with long-term conditions where there was an effect on parents' well-being. Accordingly, there may have been some bias towards identifying effects upon parental well-being from the studies reviewed. Furthermore, the second reviewer who completed the risk of bias assessment also works with this population, specifically with a paediatric neurology team, and has extensive clinical experience with children and young people with epilepsy and their families. This may have had an impact in relation to the rating of articles identified in the present systematic review.

Screening process

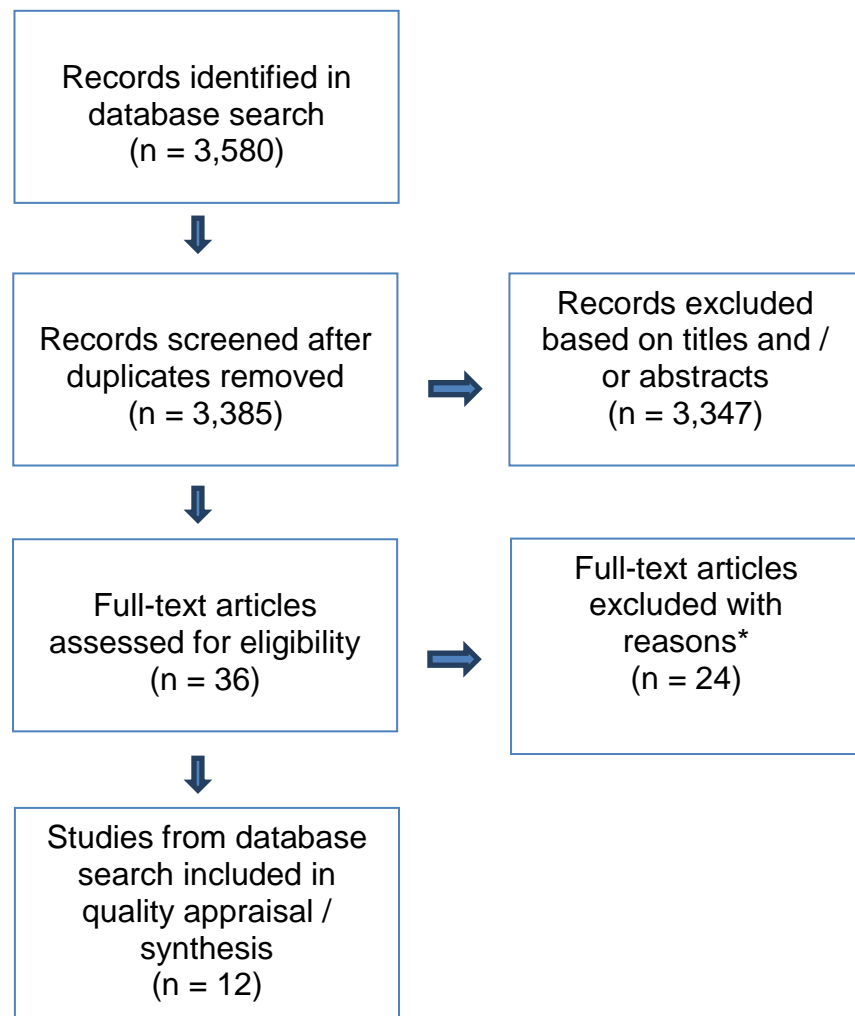
The screening process included several stages. Following the Preferred Reporting Items for Systematic Reviews (PRISMA) protocol [75], the stages

are detailed in Figure 1. Databases were searched and duplicates removed. Identified records were then imported into Mendeley [31,32]. Screened and selected articles were managed in subsequent Mendeley folders to track and record the number of records identified and retained at each step. Each record was screened manually for relevance.

Articles were initially considered relevant based on mention of the search terms in the title or abstract. When an abstract was not descriptive enough, or there was no abstract available, the full text was examined. A set of full text articles was then compiled and screened in more depth. During this process, a second reviewer was consulted to discuss two articles that initially appeared to be appropriate. However, one did not meet inclusion criteria due to the quantitative methodology used [33], and one was a PhD thesis with no subsequent identified publications [34].

A sample of 33% of papers (12 out of 36) retrieved as full-text articles were reviewed by a second rater to determine agreement on inclusion or exclusion using the criteria determined for the review. Articles were selected on the basis of a random list of numbers created using www.random.org [77], and were matched to the alphabetical order of full-text papers. The second rater agreed with the judgement of the primary researcher on 100% of the random sample.

Figure 1: Flowchart showing selection and appraisal of studies.



*See Appendix D for details of excluded articles and reasons for exclusions.

Data extraction

Descriptive summaries of the 12 identified articles are included in Table 2. Ten articles were qualitative, with two using mixed methods [35,36]. Qualitative data collection was carried out using one-to-one interviews in seven studies, with six using focus groups. One study used both focus

groups and interviews. There was variability in sample sizes (ranging from 7–71 participants). Qualitative data analysis was carried out using a range of methods: thematic analysis (n = 7); phenomenological analysis (n = 3), and content analysis (n = 1). One article [37] did not specify a method of qualitative analysis and presented a parental case study as an exemplar of semi-structured interviews. Studies were based in the USA (n = 4), Canada (n = 3) and Australia, Ireland, Taiwan, Sri Lanka and Greece (all n = 1).

Critical appraisal

Quality assessment

Following previous authors, the present review included the Critical Appraisal Skills Programme (CASP) tool [38] and a checklist for conducting systematic reviews in health care research [39,40]. This tool included ten criteria, with the extent to which each study met a given criterion assessed using a quality grading system [41]. Studies were given a score of 3 if the criterion was ‘well addressed’, 2 if ‘adequately addressed’, 1 if ‘poorly addressed’ and 0 if ‘not applicable/reported’ (see Appendix E).

Scores were summed for each criterion, with scores marked out of 30. Consistent with guidelines outlined by Cesario et al. [42], studies were then given a rating of ++ if they scored between 22–30, + if they scored between 15–21 or – if they scored less than 14. This indicated the relative risk of bias found in studies’ results: low, medium or high (see Table 3).

Enhancing rigour

Ratings were carried out independently by the author. A second reviewer also independently completed quality ratings for 100% of the articles identified within the systematic review. Prior to discussions between reviewers about ratings, there was a high agreement of 97.5% (117/120) of items (Cohen's kappa 0.958, 95% CI [76]). In the instances where there were differences, this was discussed and a rating was agreed. In general, there was a high level of consensus, with only three items requiring further discussion (see Table 3).

RESULTS

Methodological quality of studies

After applying criteria (see Table 3), two articles gained scores within the low risk of bias category, eight were within the medium risk category and two were within the high risk category. The two articles that scored within the high risk category included mixed methods.

All articles scored adequately or well covered their research aims. Three articles were assessed as not providing a clear description of context [36,43,44]. Sampling was adequately or well addressed in all articles apart from [45] where it was not reported. Data collection was assessed as adequately or well addressed by all articles, apart from [35], which did not report on this. Data analysis was not described in any of the articles. Results

appeared to be supported by the data well or adequately in 8 articles, with [36,45–47] rated as not including this. Nine articles took steps to ensure credibility, with reflexivity only not included by [35]. All studies adequately or well addressed their contribution, aside from [35], which did not report on this.

Table 2: Articles included in the systematic review and thematic synthesis.

Lead Author/ Year / Citation	Location	Aim of Research	Sample	Methods and Analysis	Qualitative Findings	Themes Relating to Parenting
Benson (2017) [52]	Ireland	To explore the challenges of parents of children with epilepsy experienced when deciding to disclose their child's epilepsy diagnosis to others	n = 34 (parents) 27 female, 7 male Age of child: 6–16 years Duration of epilepsy: 2–14.5 years. Medication: All on at least one AED Seizure type: multiple (19), complex partial (10), simple partial (4), tonic-clonic (19), tonic (5), absence (14), atonic (4), myoclonic (6), electrical status epilepticus in sleep (1). Seizure frequency: period of seizure freedom at time of interview: hours (8), days (2), weeks (5), 1–6 months (7), 7–12 months (3), 13–15 months (2). Exclusions: significant LD, learning difficulties and / or developmental delay	Semi-structured interviews Thematic analysis	Five themes were revealed including: seeking normalcy for the child, the invisibility of epilepsy, negative reactions to disclosure, contending with poor public perceptions of epilepsy and coming to terms with the diagnosis. The authors highlight that parents often conceal epilepsy from others to seek / retain normalcy, and avoid negative reactions from others, parents also have to contend with poor public understanding of epilepsy and need time to come to terms with the diagnosis.	<ul style="list-style-type: none"> • Seeking normalcy for the child • The invisibility of epilepsy • Negative reactions to disclosure • Contending with poor public perceptions of epilepsy • Coming to terms with the diagnosis
Buelow (2006) [15]	USA	To identify and explore specific causes of stress in parents of children with both epilepsy and intellectual disability	n = 21 (parents) 19 female, 2 male (including one mother/stepfather dyad) Age of child: 9–16 years (mean 12.2 years) 13 female, 7 male Duration of epilepsy: 1 month–14 years Medication: no information Seizure type: no information Seizure frequency: no information Exclusions: children without LD and epilepsy	Open-ended interviews with parents Thematic analysis	Five categories of sources of stress were identified: concern about the child, communication with healthcare providers, changes in family relationships, interactions with school and support within the community. The authors highlight sources of stress for parents including concerns about their child, a need for information, and parental support needs.	<ul style="list-style-type: none"> • Concern about the child • Communication with healthcare providers • Changes in family relationships • Interactions with school • Support within the community
Kampira (2017) [37]	Greece	To explore the challenges that parents / caregivers of children with controlled epilepsy face regarding the disorder	n = 91 (parents) 60 female, 31 male Age of child: 0–17 years Duration of epilepsy: no information Medication: no information Seizure type: no information Seizure frequency: no information Exclusions: children under 5 years old or over 17, no significant LD, learning difficulties and / or developmental delay. Parents / carers had no physical / mental health difficulties	Interviews Hermeneutic phenomenologic al thematic analysis	Two main themes were identified: the disclosure of epilepsy and the absence of information about coping with epilepsy. The authors highlight that parents were hesitant to disclose epilepsy, and also wanted more education about the condition from professionals, as well as emotional support to cope personally and as a family.	<ul style="list-style-type: none"> • Disclosure of epilepsy • The absence of information about coping with epilepsy

Lead Author/ Year / Citation	Location	Aim of Research	Sample	Methods and Analysis	Qualitative Findings	Themes Relating to Parenting
McNelis (2007)* [43]	USA	To explore the self-reported concerns and needs of children with epilepsy and their parents	n = 11 (children) Aged 7–15 years 5 female, 6 male n = 15 (parents) 12 female, 3 male Duration of epilepsy: 18 months–5 years Medication: all on at least one AED Seizure type: generalised tonic/clonic, absence, complex partial, simple partial Exclusions: children without epilepsy	Focus groups with children Focus groups with parents Thematic analysis	Themes emerging from the child data included the need for clinicians to 'talk at my level' and 'feeling different from others'. The authors highlight the difficulties and struggles parents have in caring for a child with epilepsy and the need for information to be provided at the appropriate time.	<ul style="list-style-type: none"> Difficulties / struggles / problems Need for information Fears and concerns
Mu (2008)* [50]	Taiwan	To investigate the essence of the family health to illness transition experience from a parental perspective when a child has epilepsy	n = 18 (parents; 10 couples with 2 fathers who did not participate) 10 female, 8 male Age of child: 3–7 years Duration of epilepsy: 18 months Medication: no information Seizure type: no information Seizure frequency: no information Exclusions: no moderate to serious LD	Interviews with parental couples Phenomenological analysis	Three themes emerged: psychological reactions, coping patterns and family resources. Reactions included being emotionally traumatised and physically fatigued. The authors highlight that parents coped with their emotional response and with stigma via vigilance and reframing the parental role. Parental resilience within families is noted.	<ul style="list-style-type: none"> Psychological reactions Coping patterns Family resources
Murugupillai (2016) [51]	Sri Lanka	To identify the parental concerns regarding children and adolescents	n = 16 (parents) 14 female, 2 male n = 16 (children) 5 female, 11 male Age of child: 5–18 years (mean 12 years 3 months) Duration of epilepsy: 3 days–7 years. Medication: All on at least one AED Seizure type: simple partial (9), complex partial (2), GTC (4), absence (1). Seizure frequency: > 1 per week (2), > 1 per month (3), > 1 per year (11). Exclusions: parents of children without epilepsy.	Interviews and focus groups Content analysis	Seven themes were identified: concern about children's functioning, concerns related to anti-epilepsy therapy and epilepsy as a disease, parental concern about safety, educational attainment and future prospects regarding employment and marriage, unpredictability of seizures, fear of stigma and unawareness of epilepsy, increased concern and perception of vulnerability. The authors highlight the unpredictability of seizures, fear of stigma and lack of knowledge about epilepsy were key factors in moulding parental concerns.	<p>Concerns about:</p> <ul style="list-style-type: none"> Physical functioning Behavioural / cognitive functioning Education Psychological / emotional functioning. Epilepsy in general Treatment using AEDs
Nguyen (2015)* [47]	Australia	To investigate parental narratives and experiences in the aftermath of an epilepsy diagnosis	n = 21 (parents) 21 female Age of child: 1–15 years Duration of epilepsy: 6 months – 5 years Medication: no information Seizure type: absence (5), tonic-clonic (4), myoclonic (1), simple partial (2), complex partial (4), mixed (5) Seizure frequency: no information Exclusions: diagnosis > 5 years	Semi-structured interviews with parents Thematic analysis	Analysis revealed common affective cognitive appraisals including maintaining a positive outlook, restructuring expectations and finding meaning from experience. The authors highlight problem solving, emotional venting, time to self and talking to parents with similar difficulties helped buffer carer strain.	<ul style="list-style-type: none"> The adjustment process. Cognitive appraisals. Coping behaviours

Lead Author/ Year / Citation	Location	Aim of Research	Sample	Methods and Analysis	Qualitative Findings	Themes Relating to Parenting
Nolan (2006) [49]	Canada	To investigate how parents' cope with and care for a child with Dravet syndrome (a severe myoclonic epilepsy)	n = 24 (parents) 20 female, 4 male Age of child: 2–24 years (mean 10.2 years) 11 male, 13 female Duration of epilepsy: 6–12 years Medication: no information Seizure type: no information Seizure frequency: no information Exclusions: child < 1 year old at time of study or time of death, no diagnosis of Dravet's, children did not follow the clinical evolution as described by Dravet.	Semi-structured interviews with parents Case study Quantitative analysis (questionnaires analysed using t-tests)	The authors conclude parents' experiences evolve over the course of three stages that include initial anxiety about the diagnosis to extreme stress regarding uncertainty about seizures. The authors highlight parents find all stages challenging, with parents' concerns including understanding seizure control, changes in relationships and social isolation.	No specific themes presented, but authors mention: <ul style="list-style-type: none">• Uncertainty causes stress• Negative impact on parental relationships with others• Social isolation
Roberts (2011)* [45]	Canada	To improve understanding of the school experiences of children with epilepsy and to identify the perceptions and experiences of the primary caregivers of young children	n = 7 (caregivers) Gender of parents: no information Age of child: 5–11 years Duration of epilepsy: 1–6 years Medication: All but from one on at least 1 AED Seizure type: complex partial (2), grand mal (2), absence (2), petit mal (1) Exclusions: children without epilepsy	Interviews with parents Phenomenological analysis	Five categories arose from family narratives: health related issues, family coping, academic experience, social belonging and awareness. The authors highlight that parents' worrying about their child, their feelings of uncertainty, and their having to take on an advocacy role. Social support is also noted, as is parents desire for their child to live a normal life.	<ul style="list-style-type: none">• Health related issues• Family coping• Academic experience• Social belonging• Awareness
Ronen (1999)* [48]	Canada	To identify key aspects of health-related quality of life for children with epilepsy to better inform quality-of-life instruments	n = 29 (children) Age of child: 6–10 years 18 female, 11 male n = 42 (parents) 28 female, 14 male Duration of epilepsy: 6 months–9 years (mean = 18.4 months) Medication: all on at least one AED Seizure type: partial (10); GTC (4); absence (7); absence and GTC (2); partial and GTC (5); myoclonic and absence (1) Seizure frequency: more than 2 unprovoked seizures in last 24 months Exclusions: major morbidity other than epilepsy including autism, profound LD, cerebral palsy, children easily distractible from the process; children who did not attend school regularly	Focus group with children Focus group with parents Textual thematic analysis	Five dimensions of health-related quality of life were identified: the experience of epilepsy, life fulfilment and time use, social issues, the impact of epilepsy and attribution. Parents highlighted the emotional aspects of having a child with epilepsy, on the child and on themselves. The authors highlight the impact of epilepsy on parents including reactions to stigma, limitations to family life, uncertainty and frustration.	<ul style="list-style-type: none">• Experience of epilepsy• Life fulfilment / time use• Social issues• Impact of epilepsy• Attributions

Lead Author/ Year / Citation	Location	Aim of Research	Sample	Methods and Analysis	Qualitative Findings	Themes Relating to Parenting
Smith (2014)* [44]	USA	To explore caregivers' perceptions of the caregiving process at different time periods post epilepsy diagnosis	n = 19 (caregivers) 16 female, 3 male Age of child: 1–17 years Duration of epilepsy: less than 12 months – more than 5 years Medication: All on at least one AED Seizure type: none provided. 13 – intractable epilepsy, seizures controlled in 6 CWE Seizure frequency: no details provided Exclusions: caregivers of child with comorbid diagnosis of life threatening medical condition	Focus groups with parents Thematic analysis	The main theme that emerged was navigating non-contingencies – lack of a perceived relationship between action and outcome, unpredictability. This was supported by subthemes of blessings and sacrifices, uncertainty, today and tomorrow, constant vigilance and caregiving being more than parenting. The authors highlight that similarities and differences were seen in caregiving perceptions across three post-diagnostic time periods, providing support for conceptualising caregiving as a multifactorial, multidirectional and fluid process.	<ul style="list-style-type: none"> • Lack of a perceived relationship between action and outcome • Unpredictability • Blessings and sacrifices • Uncertainty, today and tomorrow • Constant vigilance • Caregiving as more than parenting
Wu (2008) [36]	USA	To examine parents' attitudes towards mental health services, use of mental health services and other services, as well as service related and other challenges faced by parents of children with epilepsy	n = 36 (parents) Gender of parents: no information. Age of child: no information Duration of epilepsy: no information Medication: no information Seizure type: no information Seizure frequency: no information Exclusions: parents of children without epilepsy. Stratified parents by socio economic status (high / low) and ethnicity (African-American, Caucasian, Hispanic).	Focus groups Thematic analysis Quantitative analysis (Chi squared tests of coded interview content)	Themes included mental health service coverage, stigma, the need for mental health care, child emotional difficulties, parental emotional difficulties, seizures, AEDs and behavioural difficulties and medical services and educational services and academic difficulties. The authors highlight parents' concerns about misconceptions about epilepsy and stigma, which impacts on their accessing healthcare - underscoring the need for parental education and that of the public.	<ul style="list-style-type: none"> • Stigma • The need for mental health care • Child emotional difficulties • Parental emotional difficulties • Seizures • AEDs and behavioural difficulties • Medical services Educational services and academic difficulties

Abbreviations Key: AED – anti-epilepsy drugs; GTC – generalised tonic-clonic; LD – learning disability. *Article included in Harden et al. [53].

Table 3: Quality ratings of articles identified in systematic review.

Articles (First author/year)	Quality Criteria										Total Score	Global Rating
	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)		
Benson (2017)	3	3	2	2	2	0	3	2	2	2	21	+
Buelow (2006)	3	2	2	2	2	0	2	2	3	3	21	+
Kampra (2017)	3	3	2	2	2	0	2	2	2	2	20	+
McNelis (2007)	3	3	0	2	2	0	2	0	3	2	17	+
Mu (2008)	3	3	2	2	2	0	3	2	2	3	22	++
Murugupillai (2016)	2	3	3	2	2	0	2	2	2	3	21	+
Nguyen (2015)	3	3	3	3	3	0	0	3	2	3	23	++
Nolan (2006)	2	2	2	2	0	0	2	0	0	0	10	-
Roberts (2011)	3	3	2	0	2	0	0	2	2	2	16	+
Ronen (1999)	2	2	3	2	2	0	0	2	2	2	17	+
Smith (2014)	3	2	0	2	2	0	2	3	2	2	18	+
Wu (2008)	3	2	0	2	2	0	0	0	2	2	13	-

Quality Criteria

- (1) The study has a clear aim/objective.
- (2) The qualitative research design is clear and appropriate for the research aims.
- (3) Clear description of the context or setting is adequately described so the reader can relate the findings to other settings.
- (4) Sampling was suitable and participant characteristics were clearly described. Clear description of how the sample was selected and why.
- (5) The study provided a clear and systematic account of the data collection methods.
- (6) The study demonstrated a descriptive and systematic account of data analysis and included or referred to a clear data audit trail.
- (7) The results were clearly supported by the data.
- (8) Steps were taken to ensure credibility (e.g. triangulation, respondent validation, negative cases, others involved in the analysis).
- (9) Reflexivity was demonstrated (i.e. identification and examination of personal biases, effects of personal characteristics, prior assumptions, relationship between researcher and subjects).
- (10) The study contributed to existing knowledge, whilst outlining its limitations.

Quality criteria rating score (per item):

- 3 - Well addressed
- 2 - Adequately addressed
- 1 - Poorly addressed
- 0 - Not applicable/reported
(Adapted from: SIGN 50 [37])

Global rating score (per study):

- ++ = 22-30: Low risk of bias
- + = 15-21: Medium risk of bias
- = <14: High risk of bias
(Adapted from: Cesario et al. 2001) [38]).

Note: **Bold** – Reviewer 1 changed to Reviewer 2's rating; **Bold Italic** – Reviewer 2 changed to Reviewer 1's rating.

Data synthesis

Qualitative synthesis allows for the integration and contextual interpretation of qualitative research [54,55]. Although generalising individual qualitative studies is not possible, synthesis allows an exploration of commonalities across research. An increasing number of methods for synthesising qualitative research have developed, often involving adaptations of primary qualitative analytical techniques [39,54]. Barnett-Page and Thomas [56] conducted a review of published syntheses, identifying nine distinct approaches.

Thematic synthesis [55] involves the consideration of concepts and themes common across studies. The aim to produce an account of the phenomenon of interest, as a grounded theory approach aims to do with primary data analysis. Alternately, Framework synthesis [57] begins with a conceptual model of a phenomenon, which is adapted based on what is found within the literature. This overlaps with thematic synthesis as both stay close to the data, and take a less interpretative approach than methods such as meta-ethnography [58]. Meta-ethnography aims to generate an interpretative account of studies by translating concepts from individual studies into one another [59]. It is the most commonly used framework for synthesising qualitative findings [60,61]. However, Dixon-Woods et al. [54] caution it should only be used to synthesise findings when studies have comparable methodologies.

The 12 articles identified in the present review utilised a range of methodologies for data collection and analysis, hence meta-ethnography

was deemed unsuitable. As thematic synthesis can be viewed a process [55] that can be followed with multiple qualitative methods, this approach was selected as an appropriate way of aggregating the data. In addition, thematic synthesis is suitable for an emerging body of literature where there is no conceptual model to define the overall experiences of parenting a child with epilepsy.

Inclusion of articles

Estabrooks et al. [62] argue that weak qualitative articles should be excluded from data synthesis. For example, in Campbell et al.'s [60] meta-ethnography, they excluded articles that did not meet their quality standard. However, Dixon-Woods et al. [54] note that the effects of including or excluding particular qualitative findings in a synthesis, still remains to be determined. Accordingly, quality ratings did not determine inclusion or exclusion in the present review. Relatedly, the quality appraisal highlighted that none of the identified articles specified their analysis process. However, as poor reporting of methods does not equate to poorly conducted research, and as consistent with Centre for Reviews and Dissemination (CRD) recommendations [56], all studies were retained for data synthesis.

Procedure

Following assessment of quality, the thematic synthesis process described by Thomas and Harden [55] was utilised. This process uses three stages which overlap to some extent: the free line-by-line coding of the findings of

primary studies; the organisation of subsequent 'free codes' into related areas to compile 'descriptive' themes; and the development of 'analytical' themes.

Data to be included in the synthesis were considered to be the 'key concepts' presented within each of the 12 articles regarding parents' experiences of having a child with epilepsy. This included both author selected verbatim quotes from parents, as well as all text labelled 'Results' or 'Findings'. This ranged from a short 'case study' [35] to detailed author discussions that included substantive verbatim quotes (i.e. [52]). Thomas and Harden [55] note that within qualitative studies, finding key concepts is not always straightforward due to varied reporting styles. Although verbatim quotes were straightforward to identify in the identified studies, for author analysis, and as recommended by Thomas and Harden, the data was extracted from text labelled as 'results' or 'findings'.

Data were extracted and then coded, line-by-line within Microsoft Word ([63], see example in Appendix F). Codes were created inductively to capture the meaning and content of each sentence, with both verbatim quotes and author determined themes seen as equally important. The coding allowed the translation of concepts from one study to the other. Thomas and Harden [55] describe line-by-line coding as a key task in thematic synthesis, and one that is not a 'simple' translation, but which also begins the process of synthesis. As each study was coded, a 'bank' of codes was created and added to as required. No apriori framework was used, accordingly the codes

emerged from the study findings themselves. The coding process created a total of 38 codes (see Table 3).

In order to group the codes, similarities and differences between codes was assessed to begin to arrange codes into a hierarchy. Where required, new codes were created to capture the meaning of groups of initial codes. This iterative process resulted in a total of 14 descriptive themes. Descriptive themes were included if they were present in at least half of the articles. During the process of arranging codes, analytical themes began to emerge. During the line-by-line coding and initial grouping of codes, the synthesis stayed very close to the original findings of the included studies. However, at this stage the process 'goes beyond' the findings of the primary studies as dependent on the judgement and insights of the reviewer in light of the research question. Accordingly, the reviewer inferred the experiences of parents with children with epilepsy in general, as captured by the descriptive themes. Consideration was then paid to the implications of this within a healthcare context. The researcher completed this individually and in discussion with two supervisors in order to develop more abstract, analytical themes. This process was repeated until the 5 analytical themes derived appeared to be sufficiently abstract to describe and/or explain the 14 descriptive subthemes. For example, two of the descriptive themes concerned the way in which parents processed the diagnosis of their child's epilepsy (emotional impact of diagnosis, adjustment to epilepsy). From this, the reviewers inferred that parents have an emotional response to their child's diagnosis that changes over time. In a healthcare setting, this is

important to consider when planning services to meet parent's emotional needs at different stages. Altogether, the three stages as described resulted in the generation of five analytical themes, which were associated to parental experience of having a child with epilepsy.

Thematic Synthesis Results

Five themes emerged from the included studies of parents experiences: 1: Processing the diagnosis; 2: Impact of epilepsy on parents; 3: Information (sources and content); 4. Relationships with professionals / healthcare systems; and 5: Role changes: adjustment and coping. The contribution of individual articles to the generated subthemes and analytical themes is shown in Table 4, and themes are outlined below.

Table 3: Subordinate and analytical themes found in thematic synthesis.

Subordinate themes identified across studies	Resultant analytic themes and subthemes
Being told the diagnosis Psychological impact over time Difficulties communicating with professionals Lack of knowledge (parents / public) Parents seek knowledge Parents as advocates Constant vigilance Negotiating the healthcare system Withholding the diagnosis Anticipating stigma from others (peers/parents/school) Actual experience of stigma Responses from others (fear / misunderstanding / negative responses) System as uncaring Parents as decision makers Professionals as helpful experts	Time to process the diagnosis <ul style="list-style-type: none"> Emotional responses & coping Processing the diagnosis over time Impact of epilepsy on parents <ul style="list-style-type: none"> Constant vigilance Stigma (anticipated / actual) Psychological impact & coping strategies Information (sources and content) <ul style="list-style-type: none"> Parents seek / value information Types of information received Difficulties in sourcing information Relationships with professionals/healthcare system <ul style="list-style-type: none"> Professionals as experts Negotiating systems

<p> Process of diagnosis Emotional responses Uncertain future Seeking trusted professionals Expectations parents have of professionals Professionals as uncaring Mother as main advocate Role changes Coping as getting on with things Loss of expected future Need for information (various sources) Emotional impact of diagnosis Information overload Professionals as experts Seeking support (peers / family) Social isolation Change over time Future concerns/limitations to child's life Normalising epilepsy Managing uncertainty Emotional impact on child Hidden disability Accepting epilepsy </p>	<ul style="list-style-type: none"> • Communication <p>Role changes: adjustment and coping</p> <ul style="list-style-type: none"> • Parent as advocate/expert • Role changes • Benefits and sacrifices
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Table 4: Contribution of primary research to analytical themes generated via thematic synthesis.

Analytical theme:	1. Processing the diagnosis		2. The impact of epilepsy on parents			3. Information (sources and content)			4. Relationship with professionals / healthcare systems			5. Role changes: adjustment and coping		
	Emotional impact of diagnosis	Adjustment to the diagnosis	Psychological impact	Constant vigilance	Stigma	Parents seek/value information	Types of information received	Difficulties in sourcing information	Professionals as experts	Negotiating systems	Communication with professionals	Parent as advocate/expert	Role changes	Benefits and sacrifices
Subtheme:														
Article:														
Ronen (1999)		✓	✓		✓								✓	✓
Buelow (2006)	✓		✓	✓		✓	✓	✓	✓		✓	✓	✓	✓
Nolan (2006)	✓		✓											✓
McNelis (2007)	✓	✓	✓			✓	✓	✓	✓	✓	✓	✓	✓	
Wu (2008)	✓		✓	✓	✓	✓	✓		✓	✓		✓		
Mu (2008)	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓		✓
Roberts (2011)	✓	✓	✓		✓				✓	✓	✓	✓	✓	✓
Smith (2014)	✓		✓	✓	✓			✓		✓	✓	✓		✓
Nguyen (2015)	✓	✓	✓		✓	✓				✓		✓		✓
Murugupillai (2016)	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	
Benson (2017)	✓	✓	✓		✓	✓		✓	✓			✓	✓	✓
Kampra (2017)	✓		✓	✓	✓		✓	✓				✓		✓

Theme 1: Processing the diagnosis

Within most of the identified articles, authors highlighted the emotional impact on parents of finding out about their child's epilepsy diagnosis. In half the articles, a contrast between parents' initial responses and those over time was made and this was interpreted as adjustment to their child's epilepsy.

Subtheme: The emotional impact of diagnosis

Most articles included data that indicated that finding out about epilepsy was an emotionally demanding, and sometimes overwhelming, event for parents:

‘In the beginning I...I must admit I found it very hard. I mean, I used to get very upset talking about it.’ ([52], pg. 38).

Parental distress on finding out was often put in the context of concerns about the physical consequences of seizures on their child [15,36,43,45,50] and worries about what could happen to their child in the future, [37,43–45,48,51,52]. Of the two articles that did not include qualitative data regarding the impact on parents of diagnosis, one [35] included quantitative data that the initial stages of diagnosis were the most stressful for parents.

Subtheme: Adjustment to epilepsy

Half of the articles highlighted that parents appeared to come to terms with their child's epilepsy over time [43,45,47,50,52,64]:

'It does get better. Initially when she started having seizures, every seizure was terrible and you'd freak out over them. Now she might have a couple of seizures in the morning and its nothing. I still worry...but it's not as traumatic as when it first started.' ([47], pg. 27).

Parental adjustment was interpreted as being related to various factors. These included improvements in seizure control via medication, increasing experience in witnessing and managing seizures [43,47,52], parents' increasing understanding of epilepsy [43], the adjustment of expectations of their child [52] and by receiving practical and emotional support from family [50], healthcare and education professionals [45]. Overall, thus the synthesis suggests that parents have an emotional response to diagnosis, but that this changes over time as they adapt to their child's condition.

Theme 2: Impact of epilepsy on parents

The synthesis highlighted the day-to-day practical impact on parents of managing their child's epilepsy, with constant vigilance and stigma recurring themes. The psychological consequences of these issues appeared to be linked to the coping strategies that parents used. Hence, the impact of having a child with epilepsy on parents was often considered to be extensive.

Subtheme: Constant vigilance

Half of the identified articles [15,37,50,44,51] highlighted parents' constant vigilance, which seemed heightened by the unpredictability of seizures, for example.

'I've never *not* been on high alert since she started having seizures.'([15], pg. 149).

'It is really a burden. It is difficult to put into words. It's just like you are tense and you cannot relax at all. Just like waiting for a war, very nervous.' ([50], pg. 547).

In not knowing when or where a seizure might occur, parents thus seemed to responded with vigilance. Authors interpreted this in the context of the practical caregiving implications [44], for example in parents feeling responsible for ensuring the safety of their child in case of the event of a seizure [51] at home, school or in the community.

Subtheme: Stigma

Stigma was included within 9 of the 12 identified articles. This included anticipated and actual stigma. Stigma was particularly highlighted in the context of parents considering disclosing their child's epilepsy in social and educational contexts, with others' lack of understanding often emphasised:

'...it's like a hidden thing or something...like...like, I even find adults that have it don't like telling...talking about it...I don't know whether it's the stigma attached from years ago...([52] , pg.37).

Kampra et al. [37], highlight that parents appeared to neglect disclosing epilepsy where their child's seizures usually happened at night in case of bullying and isolation from peers of school staff. Wu et al. [36] interpret that misconceptions about epilepsy contribute to parents' own understandings of epilepsy, as well as the likelihood of them accessing services.

Benson et al. [52] include experiences of actual negative consequences for parents and their child, for example children being excluded from activities at school and parents having practical difficulties in finding someone to care for their child in their absence. Cultural beliefs about epilepsy were also interpreted as relevant to stigma [36,37,51].

Subtheme: Psychological impact and coping strategies

Every article included reference to the psychological consequences of caring for a child with epilepsy, emphasising anxiety, worry and sleep problems:

'Mother. It is very scary, if that (seizure attack) happens. We do not know what we can do...I am highly stressed. Every day is miserable.
Father. She (mother) is crying all day long. She cannot sleep at all. She is almost burned out. I have been very worried about my daughter and she (mother) is worse than me. ' ([50], pg. 547).

About half of the articles [37,44,50,51,65] included the ways parents subsequently utilised strategies to help them manage emotional responses associated with their child's condition:

'So, the impact was just being able to manage, and feeling comfortable when we weren't around her and having others be able to provide the proper care... for the most part, we just deal with it and we move on to allow her to have a good life and, and progress.' ([44], pg. 37).

This parent appears to find focusing on managing day-to-day as a helpful strategy to deal with, and possibly avoid, worries about the future. Parents also highlighted that they actively sought to manage their child's condition:

‘No I’m not going to lay down and say it’s all terrible and he’s going to struggle with this; we’ll do what we can to be pro-active about it.’ ([47], pg. 31).

Overall, this theme highlighted that having a child with epilepsy could be characterised by parental vigilance, concerns about stigma and thus could be psychologically challenging, and hence requires various coping strategies.

Theme 3: Information (sources and content)

Parents appeared motivated to seek information. This was often seen as a way of anxiety, adapting and effectively managing epilepsy and in understanding the prognosis. Differing types of information were sought by parents at different times and from differing sources. This seemed to depend on need: be that emotional support or help in manage the practical aspects of their child’s care.

Subtheme: Parents seek / value information

Overall, information was valued by parents, with over half of the articles including a theme or quote related to parents information seeking in relation to their child’s condition [15,36,47,50–52,65]. Parents described a need for information regarding all aspects of epilepsy, especially at the time of diagnosis and times of crisis:

‘When you first hear about it, the thing on your mind is what will be the initial treatment; you can’t go beyond that. And you don’t know how far everything goes until you really get into it’. ([65], pg. 199).

For this parent, the focus is on their need for factual information regarding treatment. This may be important in managing initial concerns on hearing the diagnosis and the related emotional response as highlighted in Theme 1.

Subtheme: Types of information

Many parents received verbal and written information from medical professionals [36,47,51,52,65,66] Factual and practical information included medical information about seizures, treatment, the cause of epilepsy, managing seizures, advice about the restriction of activities and protection from injury, and this was generally sought by parents from professionals. Practical information, for example advice on explaining epilepsy to a child or regarding available community resources, was also solicited from various sources including medics, nurses and peers.

In addition, support from friends, relatives and peers [50] was interpreted as helping parents manage their emotional responses:

‘The most important thing is for people not to feel like they are alone. Their child might be in a totally different situation with seizures, and it is important to recognise that, but to know that you are not just out there floundering in the dark is helpful.’ ([65], pg. 199).

In relation to stigma, McNelis et al. [65] also include that parents looked for of the types of information mentioned above as a way of managing the reactions of others as related to anticipated stigma.

Subtheme: Difficulties in sourcing information

While articles reported that parents received adequate information from different sources, some included the frustration and distress parents had when this was not adequate or tailored to their child's condition and how best to cope with it [37,44,50,52,64,65]. Kampra et al. [37] noted that many parents wanted information about psychosocial issues as well as medical advice, with parents struggling to know where to get such information:

‘...The doctor explained to us so many things we had to know about epilepsy. But after this visit, there was nobody else we could address and talk to more about our concerns...or at least we don't know where to find officially such a person in the hospital, in any supportive group, wherever...’ ([37], pg. 100).

Kampra et al. [37] suggest that information needs to start with the basics after diagnosis in a step-by-step approach, including medical and emotional aspects of family care. This could support the time parents need to process the diagnosis and, relatedly, McNelis et al. [65] highlight that health professionals and school staff may be a useful resource to equip with increased knowledge about epilepsy as an effective clinical intervention.

Theme 4: Relationships with professionals / healthcare systems

The relationship of parents to professionals and healthcare systems was seen as important in half of the articles [15,36,45,50,52,65]. Studies included results that reflected challenges in negotiating the relationship with professionals as experts within complex healthcare systems. Relationships

with professionals were often put in the context of being a source of stress, and the importance of communication for parents in getting their needs met is highlighted.

Subtheme: The importance of professionals

Articles included that parents were sometimes satisfied with their healthcare providers, seeing them as important and knowledgeable experts. Wu et al. note that when parents expressed trust in their medical providers and saw themselves as being 'in good hands' ([36], pg. 133), they were reassured, this was also discussed by Buelow et al. [66].

However, sometimes contact with professionals was perceived as less helpful. Wu et al. [36] discusses instances where parents thought medics did not know enough and resulting concern and confusion. Correspondingly, Mu et al. [50] detail that when parents perceived their child's condition as well controlled, this reduced stress but noted some parents monitored doctors to ensure they were providing 'proper treatment', indicating a level of mistrust and placing the parent in the role of expert about their child's condition.

McNelis et al. [65], found that participants expressed frustration when medics provided various different diagnosis and treatment plans for their child. This resulted in stress and parents feeling the need to demand clarification:

'...I think that was my biggest problem, that year by year I've had to push and shove to get everything done and to get some answers' ([65], pg. 198).

Subtheme: Negotiating systems

Parents expressed difficulties in negotiating healthcare systems, and this included difficulties contacting professionals, a lack of information and feeling that seizure frequency and medication were their only concern, regardless of side effects:

‘When I call and tell them my son has had another seizure, all they want to do is increase medications. They don’t try to get to the bottom of the problem’. ([66], pg. 149).

In addition, the number of professionals involved in a child’s care was indicated as being a frustration if parents felt side-lined regarding their child’s care:

‘I had difficulty talking to the doctor and nurses; I did not feel part of the team; the doctors and nurses never talked to my child either.’ ([65], pg. 198).

Subtheme: Communication with professionals

Communication was thus highlighted as a difficult area, with parents finding the need to monitor treatment carefully as detailed above. This also occurred with health professionals and also in educational settings:

‘I just get frustrated with the...principal, at times because he just doesn’t listen, to what you’re saying to him. And if he’s not listening; he’s not understanding.’ ([45], pg. 176).

As healthcare and educational professionals are integral to parents’ ability to process the implications of the diagnosis and learn about the condition, communication was seen within the synthesis as an important consideration

in improving services to help parents feel included and as a cornerstone of the network around the child with epilepsy.

Theme 5: Role changes

Many articles, 10 out of 12, included the changes in roles and relationships that parents experienced subsequent to their child's epilepsy diagnosis. In addition, parents were seen to discuss the benefits in challenges that arose with their child's condition.

Subtheme: Parent as advocate / expert

Most articles included themes relevant to the way in which parents' roles changed following their child's diagnosis. Mothers, in particular, talked about the need to become a 'front person' taking charge of care for their child:

'...I ended up handling most of it, physically taking care of [the child] and the insurance end of it. I was no longer mom; it got me out of that role. I became nurse caretaker; everything else and the mommy emotions were the last thing to be addressed.' ([65] pg. 199)

In relation to gender, McNelis et al. [65] highlight that mothers seemed to take on both the caregiving and decision making role regarding their child's treatment. This theme also highlights what Smith et al. [44] describe as caregiving being 'more than parenting', with parents – particularly mothers – seeking out information to educate themselves and also taking an advocacy role for their children in a variety of settings.

Subtheme: Relationship changes

Changes in marital, sibling and family relationships were discussed in half of the articles as a consequence of this focus on the child with epilepsy. One father shared:

‘I sleep real light, and, then I hear everything, and we’re so worried something’s going to happen...we just made a decision, she (mother) was going to sleep with her. And so that took the pressure off me at night and I have the ability to go to work at a hundred percent...it does change things between us, it is a big change, you try not to let it affect your life, but it does.’ ([44], pg. 38).

Buelow et al. [43] also notes that in some families, the marital relationship served as a source of support but that due to the energy required to focus on the child that poor marital relationships result, as well as difficulties in siblings communicating and getting along with their parents and each other.

Subtheme: Benefits and sacrifices

While parenting a child with epilepsy was experienced as including sacrifice, parents also demonstrated their motivation to manage the situation in the best way possible. This was indicated in 9 out of 12 articles. Parents expressed wanting to help their families maintain normalcy by minimising differential treatment by peers and avoiding the imposition of unnecessary restrictions [52]. Parents were also keen to emphasise the things their children could do, rather than what they struggled with due to their epilepsy.

‘This is a little girl, who just happens to have epilepsy. She’s very intelligent, she’s...very dynamic, she’s hilarious, she’s got epilepsy (that) just means once in a while she’s going to have a seizure’ ([54] pg. 174).

Discussion

Qualitative synthesis allows for the aggregation of the perspectives of participants across articles and, in the present review, was applied to exploring the experiences of parents with a child who has epilepsy. The results help to describe the complex processes occurring for parents of children with epilepsy, while also exploring the possible reasons for these. The thematic synthesis produced the following themes: 1: Time to process the diagnosis; 2: Impact of epilepsy on parents; 3: Information (sources and content); 4: Relationship with professionals / healthcare systems; and 5: Role changes. The themes appeared to be linked as the time taken to process the implications of the diagnosis included an immediate emotional impact, as well as time developing knowledge about their child's condition. This process appeared to be impacted on by the relationships parents have with healthcare and educational professionals and influences the way in which parents cope with, and adjust to, living with epilepsy.

In assessing the quality of the identified articles, the CASP criteria [38] assess three broad areas: i) are the results valid? ii) are they reported adequately? and iii) are results valuable? It was of note that the two articles rated as having a high risk of bias contributed least to the synthesis. Both studies used mixed methods, which can offer a valuable contribution to complex areas. However, within these articles, one [35] was notable as the authors did not include quotes from parents and included limited discussion of interview data, while the other [36] did present quotes, but with limited discussion of the meanings of these. Relatedly, articles that were assessed

as more comprehensive in their reporting of results contributed the most to the final analytical themes within the synthesis.

Importantly, the review used a broad question about parental experience and started without preconceived ideas about what would be found. The emotional distress that parents experience on initially finding out about epilepsy, as well as on an ongoing basis, was strongly indicated across the data, with most articles including this. This supports the quantitative data [15,16]. Helpfully, the qualitative evidence provides a nuanced picture of why this might be. Reasons included the task of coming to terms with the diagnosis by getting used to their child's seizures and in managing a change in expectations for the child with epilepsy. This correlates with quantitative evidence (e.g. [20]) that parental anxiety decreases over time as parents increase their understanding of the condition. In highlighting why parents of children with epilepsy experience higher levels of anxiety and depression [67,68], managing uncertainty also seems to play an important role. To cope, parents may be constantly vigilant *in case of* a seizure, hence it makes sense that anxiety might result from this state of 'high alert'.

However, it is important to acknowledge that there are a multitude of potential influences on what it is like to be a parent of a child with epilepsy. This may include the time taken for a child to receive a diagnosis of epilepsy, the type of epilepsy, the structure of the family and any additional conditions or disabilities a child may have. In attempting to aggregate data, it is key to recognise that the themes generated are likely to be influenced by these issues. While some themes were expressed similarly across the research, it

was noted that articles with a specific foci, for example on education, may not be fully represented within the analytical themes. In addition, as the participants were heterogeneous across the articles found, it is difficult to determine the influence of seizure severity in particular. This may be something to be explored in future research

Parents also voiced difficulties in accessing information after the initial diagnosis, which is an important area for clinical intervention as recommended by McNelis et al. [65]. Such intervention could improve the ability of parents to learn to gain a sense of control, adapt effectively to their child's condition and to help them access emotional and practical support for themselves. This was also included in Harden et al.'s [27] systematic review, lending support for the important role of professionals in ameliorating parental distress via educating and improving parent's knowledge of epilepsy. It may be that this could also help address any perceived stigma that parents anticipate, as a way of gaining the normalcy that Harden et al. highlight that parents seek.

Qualitative research provides an opportunity to explore the contextual factors that give rise to specific experiences. It is therefore important to acknowledge that parental research has mainly been conducted with mothers, and it is important to acknowledge the impact of gender. It has been established that on a population basis, stressful life events cause more psychological distress in women than they do in men, especially when events affect those with whom they have an emotional relationship, such as family [69]. Men and women may use different coping resources and

strategies, with men more often using problem-focused approaches and women more often using emotion-focused approaches [70]. It has therefore been suggested that coping style and the experience of psychological distress are correlated, and hence women and men may differ in their vulnerability to stressful events and the manner in which they cope with these. This may be due to the different roles played by men and women in Western society, and that their different roles often require them to cope with different problems. Research has commonly reported that women are more likely than men to have the task of coping with ill or disabled family members [71] and also usually fulfil the function of mediating between family and medical professionals [72]. Across the data identified in the review, the issue of gender was sometimes considered briefly, however this is something that could be addressed more thoroughly in future research.

Limitations of the review

Like quantitative reviews, qualitative systematic reviews and data synthesis have a defined set of steps, although the judgements within these are less definitive than they are with quantitative data. This is one of the reasons why qualitative synthesis is an ongoing area of debate in relation to the aggregation of complex data [73]. In the present review it was important to select an appropriate analysis method with justification for its use. Thematic synthesis was thus selected due to it allowing a means to draw together qualitative studies that used various methodologies while still highlighting commonalities across articles.

Thomas and Harden [55] highlight that synthesising the results of multiple studies can be difficult given the range of ways in which themes can be presented in general and also across varying methodologies. In the present study, when deriving analytical themes, it was interesting to note the articles where this was more challenging – e.g. Ronen et al. [48] did not provide comprehensive information on their themes aside from tabulated information with scant use of quotes. Also, in Murugupillai et al. [51], where content analysis was used, it was more difficult to discern full details of parents' experiences. This is relevant to debates on the utility of combining qualitative methodologies within a synthesis. It is also important to note that the idea of using an overall metric to rate the quality of studies may be unhelpful as if essential elements are missing, the rating can be boosted by the inclusion of other areas being rated. For qualitative studies, it could perhaps be argued that the importance of the way results are presented is weighted as an important area for consideration.

Also relevant is that some of the articles did not just focus on parental experiences and it is likely that this impacted on which articles contributed most to the synthesis. For example, Ronen et al. [48] focused on the child's experience as opposed to the parents', meaning that the parental quotes had a specific focus on this, albeit one which also provided information on parent's experiences. Similarly, Roberts and Whiting [45] explored the impact of a child's epilepsy on their educational experience. Thus, while information on parental experiences was included in these articles, the

extent of their influence on the synthesis was somewhat less than articles where this was the main focus.

Toye et al. [74] highlight that methods alone do not determine the quality of research for inclusion. In the present synthesis, it was evident during the synthesis process that articles which included a fuller analysis and interpretation of their data produced a fuller contribution to the analytical themes that emerged. However, as the present review only included published research, and it is possible that the inclusion of theses, grey literature and unpublished studies could have added to the synthesis and hence is a limitation.

The order in which the studies were compared may also have influenced the synthesis, with those being considered first potentially being more influential in theme generation. Some argue that rather than chronological order, articles could be completed with 'classic' articles being considered first [58]. Due to the iterative nature of thematic synthesis in generating themes, it is hoped that any such effects were mitigated.

Finally, it is also possible that the use of published literature available in the English language may have led to a risk of publication bias, accordingly any future work might also seek to include within its criteria relevant grey literature.

Conclusion

The combination of completing a quality assessment and thematic synthesis allowed a nuanced view on the experiences of parenting a child with

epilepsy. It was found that parenting a child with epilepsy can have a wide reaching emotional impact on parents themselves, on their relationship with healthcare providers, and on their way of processing and adjusting to the diagnosis. For parents, processing the diagnosis seemed to include making sense of epilepsy and understanding its implications, while adaptation involved changing over time by learning more about epilepsy and how to manage the uncertainty of it. The present review is in line with results from quantitative research that parents with children with epilepsy experience more emotional difficulties, and suggests possible nuanced reasons for why this might be the case. Within this, gaps have been highlighted as to where professionals can improve their support of parents, moving from a narrow focus on medication and seizure control and broadening out to the practical and emotional impact of caring for a child with a long-term condition and ways in which to support this.

Conflict of interest declaration

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Systematic Review Word Count

11,787 words (including figures, tables and citations).

Chapter 3: Empirical Research Journal Article

Mothers' experiences of being told about the risk of sudden unexpected death in epilepsy for their child (SUDEP): An Interpretative Phenomenological Analysis

Written in accordance with author guidelines for:

Epilepsy & Behaviour (see Appendix G).

Abbreviated title for running head:

Mothers' experiences of being told about SUDEP

Keywords:

SUDEP

Epilepsy

Children

Mothers

Qualitative

Interpretative Phenomenological Analysis

Empirical Study Abstract

Background: Although there is research about how parents cope with parenting their child with epilepsy, little is known about how parents experience being told about the risk of Sudden Unexpected Death in Epilepsy (SUDEP) for their child. Relatedly, there is little guidance on when, how and what clinicians should tell parents about SUDEP.

Aims: To explore mothers' experiences of being told about the risk of SUDEP for their child and to provide clinical recommendations based on the findings. Mothers were interviewed as research indicates they are more likely to have the role of caring for ill family members than fathers.

Method: Eleven mothers of children with epilepsy were selected using purposive sampling from two Scottish NHS health board locations. Semi-structured interviews were conducted with participants, with the aim of discussing their experience of being told about SUDEP and the impact of this over the course of their child having epilepsy. Interpretative Phenomenological Analysis (IPA) was used as the study methodology.

Findings: Data analysis revealed five superordinate themes that captured the extensive and largely challenging impact of being told, and subsequently knowing, about the risk of SUDEP. These themes were labelled: Finding Out About SUDEP, Perception of Risk, Managing Uncertainty, The Impact of SUDEP, and Knowledge and Understanding of SUDEP. The themes

represented mothers' attempts to understand and process information about SUDEP and cope with and integrate this into their daily life.

Conclusions: Mothers were found to be motivated to understand SUDEP. They often appeared to overestimate the risk of SUDEP and coped with their resulting distress by using varying strategies. This included attempts to understand SUDEP, although this was difficult where they felt that too much information was provided, information was not relevant for their child, or it was difficult to understand. In understanding mothers' experiences, clinicians can adapt how they provide information to support parents in understanding SUDEP. Mothers' recommendations included informing parents about SUDEP as soon as possible, tailoring information to parents' existing knowledge, making information understandable and making specific reference to the actual risk, perhaps using comparisons and taking time to discuss any questions. These measures may help to minimise the likelihood of parents overestimating risk, which may moderate any distressing psychological impact.

Introduction

Sudden Unexpected Death in Epilepsy (SUDEP) is a death that is sudden, unexpected, witnessed or unwitnessed, not related to a traumatic event such as a head injury or drowning in patients with epilepsy, with or without evidence of a seizure and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicologic or anatomical cause of death [1,2]. SUDEP is a potentially preventable cause of death during childhood. Accordingly, supporting parents to understand SUDEP, and hence potentially increasing adherence to treatment, should be a goal of clinicians [3]. To do this effectively it is important to understand parental experiences of being told about SUDEP. As a neglected research area, this was the focus of the present study.

At present, the evidence regarding incidence rates and risk factors for SUDEP is relatively poorly understood. Harden et al. [4] conducted a systematic review and found there was considerable uncertainty regarding estimates of the risk of SUDEP in adults with epilepsy. However, following their review of the available literature they determined the incidence as occurring in 1 in 1,000 adults with epilepsy per year [5,6]. Incident rates in children (aged 0–17 years), were found to be more reliable and lower than that of adults; with recommendations to report the rate as 1 in 4,500 [4,7]. Ficker et al. [8] identify SUDEP as a rare cause of death within the overall population of those with epilepsy, although it exceeds the expected rate of sudden death in the general population by nearly 24 times. For children, the risk of SUDEP is about 4 times that of the general population.

The best established risk factors for SUDEP, shown mainly within an adult population, are frequent generalised tonic-clonic seizures, nocturnal seizures and poor adherence to anticonvulsant medication [4,6]. A slightly increased risk for males has also been reported [9]. For children, risk factors are less well established, but limited evidence suggests that children with more severe epilepsy and those with comorbid conditions are at a higher risk [7]. Childhood-onset epilepsy has been found to be a risk-factor in SUDEP during young adulthood, with the risk reported as 7% in a 40-year follow-up study of childhood-onset epilepsy [10].

The mechanism by which SUDEP occurs is similarly not yet fully understood, although almost all witnessed cases of SUDEP are associated with a seizure [11]. The large SUDEP risk increase from generalised tonic-clonic seizures alongside epilepsy monitoring evidence [12] strongly suggests that this type of seizure is a causal path to SUDEP [4]. In addition, it has been observed that respiratory depression following a seizure could be another possible mechanism [13].

It is acknowledged that there is no means of eliminating SUDEP [5,11] and a younger age and early onset of epilepsy cannot be altered. However, increasing adherence to medical interventions, particularly anti-epileptic medication, can reduce the frequency of uncontrolled seizures [14]. Nocturnal monitoring has therefore been suggested as a way to reduce the risk of SUDEP via the early identification of seizures that may require intervention [15]. Given that parents will tend to be responsible for such management behaviours, it is important to consider how best to approach providing them with information on SUDEP.

Recently, there has been significant debate regarding the importance of disclosing the risk of SUDEP to individuals with epilepsy and parents of children with epilepsy [16]. National guidance currently states families have a right to clear, accurate and appropriate information about SUDEP, related prevention strategies and resulting implications for day-to-day living [17,18]. The provision of information on SUDEP also depends on the certainty of the epilepsy diagnosis. While SIGN provides a checklist that includes advice on how to conduct a discussion about SUDEP, there is no direction on how and when to provide this information within this or NICE guidance.

Despite recommendations on disclosing SUDEP, actual practice regarding this has been found to be variable. In the UK, Morton et al. [19] analysed 387 questionnaires on the practice habits of UK-based neurologists, finding that about 70% discussed SUDEP with 'very few' or 'none' of their patients. Similarly, a recent Italian study [20] found only a minority of clinicians discussed SUDEP with adults with epilepsy, and this was often only if they requested information themselves. Research also suggests that there is inconsistency regarding whether or not clinicians discuss SUDEP with the parents of children with epilepsy [21]. Gayatri et al. [22] examined the provision of SUDEP information by paediatric neurologists and found the majority (74%) of paediatric neurologists only provided SUDEP information where children experienced intractable seizures and that neurologists were uncertain about the effect that SUDEP disclosure would have on parents or their children.

Indeed, Friedman et al. [23] found that neurologists often anticipated a negative reaction to discussions regarding SUDEP. In addition, Miller et al.

[24] completed focus groups with American clinicians about their reasons for discussing SUDEP, and found that clinicians expressed reluctance to discuss SUDEP if they felt it was morally wrong to provide information on a poorly understood and difficult to prevent complication of epilepsy.

However, the idea of withholding SUDEP information is not necessarily supported by those with epilepsy or by parents who have children with epilepsy. Morton et al. [19] found that bereaved relatives of adults with epilepsy who had died as a result of SUDEP indicated they would have preferred their relative had been informed to give them the opportunity to make choices about treatment and risk management. Relatedly, Harden et al. [25] interviewed young adults with epilepsy in Scotland and they too wanted to know about the risk of SUDEP. Ramachandran et al. [26] conducted focus groups with bereaved relatives, including parents, of individuals with epilepsy who had been identified as having died due to SUDEP. They similarly found that these families wished they and their relative had been told about SUDEP, specifically during initial discussions about epilepsy, with emphasis that information should not be learnt via the internet or from an information leaflet.

Currently, relatively little is known about how parents respond when they are told about SUDEP. In Gayatri et al. [22], parents were given questionnaires immediately after they were told about SUDEP, with 16% and 35%, reporting that they were 'shocked' and 'worried', respectively, about SUDEP. While this quantitative information is helpful, it does not look at how parents understood and subsequently coped with the information they were given.

Research on the issue of gender and coping has established that difficult or challenging life events are more likely to cause psychological distress in women than they do in men, especially when these affect family members [27]. It has also been suggested that men and women use different coping resources and strategies than women when such events occur [28]. Relatedly, research has commonly reported that women are more likely than men to provide care for ill or disabled family members [29] and often fulfil the task of mediating between family and healthcare professionals [30].

Additionally, the significance of illness may be different for men and women. In particular, women are more likely to blame themselves for their child's difficulties and have their identities threatened by illness and disability in their children [31]. Interestingly, these differences are not just a reflection of the difference in domestic duties and outside employment. In a qualitative study on gender roles and mental health, Sigmon [28] found that even when men and women experience the same conflicts regarding home or work, their interpretation of these conflicts is different. It may therefore be important to consider the experiences of mothers and fathers separately, due to the potential differences in how they may respond to discussions of SUDEP regarding their children.

In summary, it has been found that the actual risk of SUDEP in children with epilepsy is low. Despite guidelines directing clinicians to discuss SUDEP with parents of children with epilepsy, they are often reluctant to do this due to concerns about the possible distress this may cause. Conversely, it has been found that parents want to know this information. Little is known about parents' experience of being told about SUDEP. In addition, mothers' often

take on the majority of caregiving where a child is unwell. The present study makes an assumption that the relationships between gender, stressful events and coping could be grounded in the gender roles assigned to men and women in our culture. Accordingly, the present study aimed to explore mothers' experiences of being told about SUDEP in order to understand the psychological impact of this event as well as determining how best clinicians might approach disclosing SUDEP.

Methods

Participants

Participants were 11 mothers of children (aged 5 to 12 years) who had been given a diagnosis of epilepsy. All children were currently under the care of paediatric neurology services. Participants (mothers) were over 18, able to give informed consent, and were fluent in English. All participants had a previously documented discussion with their child's doctor or specialist epilepsy nurse about the risk of SUDEP. This was confirmed by clinicians following a review of medical records to ensure parents had been informed of SUDEP risk in their child. Participants were not included if they had participated in other clinical research in the past 12 months (to relieve potential burden caused by the cumulative effects of participation in multiple studies) or if their child was an inpatient. This was important to consider as a child who is an inpatient may be at increased risk of poorer seizure control and parents may experience increased levels of anxiety about their child's epilepsy.

As the age range of the children was relatively broad (aged 5 to 12 years), homogeneity was not assumed. However, to have a sample as homogenous as possible, infants were excluded, as were teenagers where there would be additional sources of risk and/or potential evidence of poorer medication adherence. Young children necessarily require more direct care. Variation in parenting behaviour is thus limited by the fact that parents cannot leave infants alone for long periods of time and are likely to be more sensitive to any indicators of ill health. In addition, concerns surrounding Sudden Infant Death Syndrome (SIDS) may be a possible confounding factor with SUDEP. With adolescents specifically there is a potential shift to the adolescent taking more control of their epilepsy, thus changes to the kinds of risks to be considered; adolescents are generally seen within teenage clinics that prepare for this transition and thus potentially have additional conversations related to SUDEP. It is also of note that seizure severity differed across the children. However, the aim was to provide a transparent and contextualised analysis of the participants to allow a clear evaluation of the transferability to people in contexts that are more or less similar. In qualitative research, the aim is to examine the experience of a specific, clearly defined group and accordingly purposive sampling can be appropriate [32]. This kind of sampling involves identifying and selecting individuals that are knowledgeable about a particular phenomenon of interest and can communicate their experiences, as opposed to randomisation where the generalisability of findings aims to minimise the potential for bias [33].

Recruitment

Participants were recruited through paediatric neurology services within two Scottish NHS Health Boards after gaining ethical approval (see Appendix H). The following process was followed to gain informed consent. Consultant paediatric neurologists identified possible participants who appeared to meet inclusion criteria. A cover letter (see Appendix I) and participant information sheet (Appendix J) was provided by neurologists to mothers, who were asked to fill out and sign a contact form, which indicated they would like to be contacted by the Chief Investigator (via phone, e-mail or letter) to find out more about the study. Participants could return the form directly to the neurologist, or post it to the researcher indicating that they would like to find out further information. It was made clear on the contact form and information sheet that initial contact was to find out more information and did not constitute consent to participate.

The researcher (HG) contacted all potential participants using their preferred method to arrange a discussion about the study. If potential participants were interested in taking part, a mutually suitable time to meet for a face-to-face interview was arranged at an NHS-based location or at the participant's home. Skype was also offered, while Skype is a new medium for qualitative data gathering, it has been used successfully in research [34] and has been evaluated as a suitable research tool, with guidance for its usage produced [35]. However, no participants chose this option. At interview, information regarding the study was reiterated and formal consent was obtained (see Appendix K).

It was highlighted that the clinical care given to their child was unaffected by the parent's participation or not. Participants were also informed they could withdraw consent during data collection (interview), with the opportunity to stop their interview at any point, take breaks and subsequently commence participation or withdraw consent completely. Participants had access to an Epilepsy Specialist Nurse who provides ongoing psychological support to families.

Demographic information was collected at the point of interview (Appendix L). Participants were informed that due to the nature of the transcription and analysis process of the research method being used, withdrawal of consent was not possible following data transcription. Participants were provided with a timeframe for this at interview (which was always at least three weeks or more) within which they could withdraw consent for their data to be used. If a participant wished to withdraw consent at the point of interview or during the time between interview and transcription, data would have been destroyed. No participants requested to withdraw consent during recruitment or in the post-interview time period prior to transcription.

Participants were asked if they consented to being contacted for feedback on the interpretation of their transcribed interview and six consented to this. Three participants were contacted in order to gather feedback following analysis, however only one responded within the available timeframe. The one participant who gave feedback on the interpretation agreed that it was coherent and resonated with her experience (see Appendix P).

Interview procedure

Interviews took place at two NHS locations or were conducted at the participant's home, and in one instance at a participant's place of work. Participants were invited to offer a rich, detailed first-person verbal account of their experiences. A limit of 60 minutes of discussion was placed to avoid undue demands on participants, but with sufficient time to gather data. Interviews ranged from 18 minutes to 55 minutes (mean 30 minutes). The researcher (HG) collected and transcribed all data.

A semi-structured one-to-one interview format was utilised using an interview schedule with four open questions with prompts (see Appendix L) that aimed to generate discussion. Topics covered in the schedule included what participants remembered about being told about SUDEP, what this was like for them, if this impacted on their relationship with their child, and what they believed clinicians should tell parents. The questions in the schedule were linked to the research questions. Initially, broad topics were identified by a group of Paediatric Neurologists and these and potential prompts were refined via a review of literature (which is included within the present article's introduction) as well as consultancy with Epilepsy Specialist Nurses and consultation with two parents of children diagnosed with epilepsy.

To quality check interview data, halfway through data collection interview feedback was sought from a clinical psychologist with experience in qualitative research who listened to and provided feedback on two interview audio recordings. Feedback focused on ensuring the same questions were

asked of all remaining participants and highlighted the strong emotional content.

Demographic variables were collected at interview from all participants regarding their child with epilepsy (Table 1). It was anticipated that this information could have a bearing on any contrasts between participants in finding out and making sense of SUDEP.

Ethical issues

Data were anonymised and stored in line with NHS policy. An encrypted, password protected audio recording device and computer were used and these were stored within a locked cabinet in a locked office on NHS property. Data were transcribed as quickly as possible after interviews were conducted and the transcripts anonymised. Audio files were stored on a secure network in accordance with NHS and Edinburgh University protocols for secure data storage. The research proposal for this project was approved by NHS Tayside, NHS Lothian and the East of Scotland Research Ethics Service (see Appendix H).

Qualitative analysis

The study used Interpretative Phenomenological Analysis (IPA), which focuses on the way an individual experiences the world within a particular context [36]. The aim of IPA is to explore in detail the processes through which participants make sense of their experiences by examining their responses to those experiences and attempting to find and interpret what is

happening and the reasons why this might occur [37,38]. Smith and Osborn [39] note that IPA is useful where research aims to consider illness narratives that occur over time and the complexities within this process. For these reasons, IPA was determined to be an appropriate methodology as opposed to grounded theory which aims to provide a theory to explain an experience [40], or thematic analysis where experiences are described and practices of a population studied [41].

Recommendations suggest that 6–12 participants are sufficient to understanding common perceptions and experience among a group of relatively homogenous individuals [42], thus 12–15 participants were sought. It was anticipated this would provide a sample size of approximately 10–12, given the potential for participants to withdraw consent during recruitment. Smith et al. [43] suggest that a sample size of between 4 and 10 interviews is appropriate for IPA research. Successful analysis requires time, reflection and dialogue, and larger datasets may inhibit this.

Table 1: Demographic information of participants' and their child with epilepsy.

Participant	Age of child	Gender of child	Age of diagnosis	Type of seizure disorder	No. of epilepsy medications child takes (at time of interview)	Other diagnoses (e.g. developmental disorder)	Seizure frequency
1	12	Male	7 years	Epilepsy	2	Ataxia Visual cerebral impairment	Less than 1 a month
2	11	Male	5 months	Lennox-Gastaut Syndrome Tonic clinic seizures	3	Lissencephaly	1 or more a day
3	12	Male	2 years	Absence seizures	1	None	Less than 1 a month
4	11	Female	3 years	Frontal lobe seizures	3	Learning difficulties	Other – week prior to interview had 30 in one week, prior to this 3–4 seizures a night.
5	10	Male	1 year	Complex partial temporal lobe seizures	1	Autism Global developmental delay	Less than 1 a month
6	10	Female	9 years	Tonic clonic seizures	1	None	1 or more a month
7	10	Female	6 years	Partial seizures	1	None	Less than 1 a month
8	11	Female	10 years	Tonic clonic seizures Absence seizures	2	None	1 or more a week
9	7	Male	1 year	Temporal lobe seizures	1	None	Less than 1 a month
10	10	Male	6 months	Complex seizures	1	Global developmental delay Cerebral palsy	Less than 1 a month
11	7	Male	10 months	Tonic clonic, absence and partial seizures	3	Autism	1 or more a week

Data from 11 interviews were analysed according to the comprehensive description of IPA provided by Smith et al. [43]. In brief, steps included: a line-by-line analysis of each transcript looking at the experiential claims, concerns and understandings of each participant; emergent themes were then identified from the transcribed material highlighting convergence and divergence, commonality and nuance across all interviews. Subsequently, the development of a 'dialogue' between the researcher, the line-by-line coded data, and their psychological knowledge, was developed regarding what it might mean for participants to have the concerns identified within this context. This led to the development of an interpretative account of the data and of a structure that illustrates the relationship between the identified themes.

Organisation of material was completed within a format that allowed for the analysed data to be followed from initial comments on the transcript, through the identification of emergent themes and then final theme identification. An experienced IPA researcher oversaw the analysis at all stages. Two transcripts were independently coded and this analysis was checked with the researcher as quality control as well as sharing the final interpretation of themes.

Reflexivity

Blumer describes the assumption and prior knowledge of a researcher as 'sensitising concepts' [44]. Accordingly, it is helpful to situate the experience of the researcher as a trainee clinical psychologist with an interest in the impact of long-term health conditions. A reflective diary of reflections and

interpretations was kept during the research process (see Appendix P). Instead of considering researcher bias as a barrier, interpretations were considered to be an integral context to the process from interviewing, transcription and when analysing the resulting data.

Results

Analysis of the data highlighted the emergence of five superordinate themes, which were labelled 'Finding Out About SUDEP', 'Perception of Risk', 'The Impact of SUDEP', 'Managing Uncertainty', and 'Knowledge and Understanding of SUDEP'. Each superordinate theme includes subthemes, which are exemplified with verbatim quotes. Subthemes were included if they appeared in half or more of the interviews. The contribution of interviews to each theme is presented in Table 2 and a representation of the links between themes is shown in Figure 1. A sample coded transcript is included in Appendix M.

Table 2: Contribution of participants to themes.

SUPERORDINATE THEMES	Finding Out About SUDEP		Perception of Risk		Managing Uncertainty			The Impact of SUDEP		Knowledge and Understanding of SUDEP	
	Coping with being told	Seeking information	Perception of risk	Processing information	Coping strategies	Seeking support	Anticipating loss	Psychological impact	Role change and identity	Meaning making	How should parents be told?
P01	√	√	√	√	√	√		√		√	√
P02	√	√		√	√	√	√	√	√	√	√
P03	√	√	√	√	√	√					√
P04	√	√	√	√	√	√		√		√	√
P05	√	√	√		√	√		√	√		√
P06	√		√		√			√			√
P07	√	√	√			√	√	√	√	√	√
P08	√	√				√		√			√
P09	√	√	√	√		√	√	√		√	√
P010	√	√		√	√	√	√	√	√		√
P011	√	√	√		√	√	√	√	√	√	√

Theme 1: Finding Out About SUDEP

Coping with being told

All participants described the way in which they had been told about SUDEP, with many describing their emotional response to finding out:

‘We first had our first discussion on it when [child’s name] was diagnosed with his condition, and my question initially to his consultant was...is he going to die? I found it very frightening.’ (P11).

The effect of this quote is to highlight the central purpose of this interpretation; that finding out about SUDEP can have a dramatic impact on mothers. For this mother, finding out immediately brought to mind the possibility of her child dying and her understandable fear of this possibility. Most mothers received information on SUDEP in the context of being told about their child’s epilepsy diagnosis, which they often talked about as stressful, but finding out about SUDEP in particular was often described as having an immediate and negative impact:

‘Just thinking...*please* don't let it happen to her. Don't let it be her. Don't let her be the one that it kind of happens to. Hoping that it's just going to be...it's not going to be her.’ (P06).

In this extract, what is striking is the sense of a parent trying to cope by focusing on her hope that SUDEP would not happen to her child. For most participants, it seemed clear that finding out about SUDEP was not just receiving a piece of neutral information, rather it was talked about as a difficult and emotional event. Importantly, the way mothers responded to finding out often made reference to the knowledge they already had, or did not have, about SUDEP. For those with some knowledge of SUDEP, there

was a sense of surprise on hearing that it was something that needed to be considered for their child:

‘I felt totally ignorant. You know, one mum said to me, have you heard about this SUDEP and I was like, no. And when, when I asked about it, I really thought they were going to say it's not E's type of epilepsy so we don't have to worry about it. I really didn't think I'd get the answer I did.’ (P04).

This extract could be seen to demonstrate that although this mother knew something about SUDEP, there was an initial denial that it could be relevant to her child. It also highlights the importance of mothers' knowledge and understanding of SUDEP relating to how they understood it initially. Interestingly, one mother who had a family history of epilepsy said:

‘I think because we've lived with it, my brother had childhood epilepsy you see and...em...we just kind of took it in our stride, em. We weren't worried, worried – but you know...’(P03).

This interview seemed to be in contrast to others due to the calm way this mother described finding out about SUDEP. It could be that her family experience of epilepsy lessened her concern about SUDEP. This participant explained that her brother had well controlled epilepsy that had had a limited impact on his life. Her concern was correspondingly not as high as the participants above who had less initial knowledge about epilepsy in general, and of SUDEP in particular.

Seeking information

Linked to the experience of finding out about SUDEP, mothers talked about their subsequent motivation to know more about it:

‘I need to know as you are going to send me away from this hospital and I'm going to be expected to look after this little boy, who I have no idea what's going on (pause). You need to be honest with me.’ (P02).

‘...I'm like – tell me everything! Tell me everything. Don't hide anything from me, so. I like to know and I, I like to be prepared. For anything and everything. Yeah.’ (P07).

For these mothers, it was evident they wanted know as much as they possibly could about SUDEP and this was referred to throughout their interviews. There was a sense that this was linked to an experience of anxiety about knowing how best to care for their child. In considering this, it makes sense that knowing as much as possible may be a way to manage their concern about SUDEP. Correspondingly, participants described looking for information on SUDEP from various sources. As referred to above, one participant talked of utilising her family knowledge:

‘...actually, I just spoke to my mum about it, because she had gone through it all before.’ (P03).

For those without this resource, the internet was often utilised. However, mothers’ experiences of finding SUDEP information online was often described as worrying, unhelpful and confusing as they tried to work out what was relevant amongst an overwhelming amount of information.

‘...it's difficult em and when you go online it goes into all these eh clinical trials and it's sort of above your head what they're talking about you know. It's trying to pick out bits of information that you can equate to.’ (P05).

In some cases, such experiences were compounded by contact, or lack thereof, with professionals:

‘...you've only got a very short time to ask questions and when you're doing your own research you come across things that you need to ask questions about...I definitely think that people need, need the hard facts to then ask the questions rather than obviously finding it out from the internet cos sometimes that's not a good thing.’ (P08).

If a parent has not had an opportunity to ask questions in relation to their child, opportunities are lost to provide parents with evidence-based information about SUDEP. However, one parent contrastingly said:

‘No, no, I've not looked any further into any of that. I just dread kind of looking further...’ (P06).

Therefore, while most mothers spoke about wanting to know as much as possible, this mother's fear seems to be leading to an avoidance of knowing more.

Theme 2: Perception of Risk

Heightened perception of risk

Many mothers talked about their understanding of the likelihood of SUDEP. None appeared to underestimate the risk of SUDEP; more commonly, risk was appraised as being high:

‘I worried constantly, I ended up sleeping in his room em on the floor on a blow-up mattress till I got the monitor and even then I didn't know how much to trust that, would it pick it up or would it not?’ (P04).

For this participant, her initial exposure to SUDEP was reading an article from a local newspaper featuring a child who had died from SUDEP. Although she had subsequently been told by her consultant the risk for her child was very low, her appraisal of the likelihood was high enough to prompt

her to obtain, and continually test, equipment to monitor her child. Similar attempts to monitor children were mentioned across the interviews where mothers appraised the risk of SUDEP as high. It could be that an overestimation of risk links to the efforts made by parents to manage their sense of imminent danger. Relatedly, participants talked about the effect of minimising their perception of risk by comparing SUDEP to unlikely events:

‘I found it really helpful when they were explaining that anybody could die in their sleep. And that it's just a slightly increased risk, because that's the only thing that's really stuck in my mind. You know, that it could happen to anybody and you're only slightly more at risk with epilepsy but it's still small... it's a possibility, but it's not a certainty, you know.’ (P09).

In emphasising that *anyone* could suddenly die, regardless of epilepsy, this participant could be seen as reassuring herself that the risk is small.

Processing at different stages of the journey

Related to perception of risk, mothers said that they process information about SUDEP differently at different time points. One mother described her experience over time from the point of being told:

‘Erm, I think at the time you are a bit numb, you just go through, you just go through the situation, em but you are, you are – it's like you are just, I don't know, eh...numb. You just do it, you know, do it without actually thinking. And it's not until things get, until things get better you think goodness every night I used to, I used to you know, you didn't sleep...it's not until you are out of the situation that you realise what you've actually gone through.’ (P01).

This mother acknowledges that initially she was overwhelmed to the extent that she felt ‘numb’. This could explain her difficulty in processing information about SUDEP. It wasn't until later that she was able to reflect on her

experience. Relatedly, other mothers talked of changes in their parenting over time:

‘I was a wee bit scared when he started his swimming lessons, em but obviously they're in the pool with the instructors and things so...like I was a wee bit of a helicopter parent when he was really wee, but I've backed off a bit now.’ (P09).

The use of the phrase ‘helicopter parent’ sums up her initial desire to supervise her child all the time, but this changed, reflecting a potential change in her perception of risk over time, which seemed to be related to an increase in her knowledge about SUPEP.

Theme 3: The Impact of SUDEP

Psychological impact

Every participant discussed the psychological impact of finding out and knowing about SUDEP, with many describing it as anxiety provoking with an ongoing impact on their feelings, thoughts and behaviour:

‘I don't think I've slept properly for about 12 years. I'm exhausted, and I'm...I have been diagnosed with depression and stuff as well.’ (P02).

Participants often mentioned difficulties related to stress including sleep problems, difficulty relaxing and some noted feelings of panic. Throughout the themes, there is a thread of worry and anticipatory anxiety about what could happen that is evident in the way participants talked about their experiences. Consequently, some mentioned wanting support:

‘I mean it was only last month that I thought I need to go and see a counsellor or something. (P08).

The degree to which parents appeared to express anxiety seemed to be related to how likely they thought SUDEP was for their child, regardless of the actual risk.

Role change and identity

Participants talked about the impact on their lives in terms of a change in role, and how this had changed their view of themselves:

‘I was quite a happy-go-lucky person, nothing...nothing really phased me before. No, you're just going along in your life thinking, oh well got kids, got a house, got a job you know...holidays and that...seemed to me a perfect wee life. I don't think I understood the impact of a sick child on a family.’ (P11).

This participant often compared her life now to her life before her child was diagnosed with epilepsy. This could be seen in the context of caring for a child with a long-term condition as opposed to being directly linked to SUDEP, although it is possible there is a link. One participant in particular seemed to have made significant life changes:

‘I've had to give up my job now because P's seizures are just...there's no way around it just now. Not at the moment...I've always worked ever since I was thirteen, so I always worked and that. And having to give that up was a bit of a...(long pause)...it's not good. But, it was a...she has to come first.’ (P08).

This participant expressed a high degree of anxiety about SUDEP, and it is possible that this was a contributory factor in her decision to stop working.

Theme 4: Managing Uncertainty

Trying to cope

Mothers coped in different ways with the idea of SUDEP being a possibility for their child. Some talked about attempts to 'just get on' with life:

'You just do things, to try and keep going as best as you can because there's not just the one child, there's the other two that are there as well and you have to...you just go a bit numb. Autopilot (laughs) is what I would call it! (P01).

This mother describes a need to keep things going, possibly focusing on what needs to be done in the here and now as a practical necessity, with her reference to feeling numb an indication of how overwhelming this feels. Coping with thoughts of SUDEP were correspondingly talked about in an all or nothing way: either you think about SUDEP all the time and cannot cope, or you try not to think about it and can cope:

'I thought, I cannae live like that...because if I live thinking that all the time I'll never go to sleep again (laughs). And I'm not going to be able to function properly, eh! I have to kind of put it to the back of my mind. Try and get on with it....as normal as I can...it is scary, yeah.' (P06).

Linked to the idea of avoiding thoughts as a cognitive coping strategy, some mothers described a process of planning as much as possible:

'And you know everything's like a constant – what do I need to do, how do I need to do it? What if this happens, you need to plan for that, you know everything's constantly – you know I have a Gran in [place name] and I wonder how long it'd take us to get to [hospital name] from there. If he had a seizure and I had to phone an ambulance, probably not that long actually...' (P02).

Here, it could be that planning ahead is a form of worrying that gives this mother a sense of control over her experience, which helps her manage her fear.

Seeking support

Alongside the coping strategies mentioned, participants discussed seeking emotional and practical support. Family support was frequently mentioned, although sometimes this was limited:

‘Yeah, I’ve spoken to my mum and my husband and some of my friends as well. My mum’s a worrier, so I try not to give her any more to worry about than she needs to.’ (P04).

As a consequence of some mothers not wanting to burden their families with the stress they were experiencing, peer support was seen as helpful. One mother described an online forum she was on as:

‘...Like a little family, you know what I mean, a group of people where all of the kids are different, none of them are the same...but it is a massively massively supportive network. And we...they’ve been involved in our lives since [child’s name] was quite small.’ (P02).

Conversely, some mothers found the prospect of peer support unhelpful:

‘I’ll just be honest. I think unless...someone has the exact same experience that you’ve had, sometimes I don’t think it’s helpful’ (P04).

Theme 5: Knowledge and Understanding of SUDEP

Searching for meaning

Linked to the knowledge that mothers gained over time is how they tried to understand SUDEP and what it meant for their child. This seemed to be

linked to interpreting risk in a personally meaningful way. Often comparisons to other health conditions were used. One mother whose child has a high risk of SUDEP said:

‘I always explain it to people in that fact that when you first have a baby, the first six months a baby is at a high risk of cot death so, you know, every morning you poke them if they're not moving, make sure they wake up. [child's name] is nearly 12 years old and I still do that every morning.’ (P02).

This mother referred to cot death throughout her interview, highlighting that this is key to her understanding. Each morning she checks to see if her child is still alive. The stark nature of this puts into sharp relief why she might approach each morning with trepidation. As her child's actual risk was higher than many of the other participants, this comparison makes sense. Other parents whose children had a lower risk, also compared risk to their own health conditions or that of others they knew about:

‘I tried to sort of, the way it was put to me that it can happen, but a child could die from an asthma attack and myself having that condition when I was a child, that kind of reassured me it was OK, you know what I mean. It's a possibility, but it may happen, it may not. And that's how I dealt with it.’ (P05).

‘Her best friend has diabetes, so the two of them are quite a wee pair! You know, so I think, I think that's helped her understand that actually I'm taking tablets twice a day and you know whereas [friend's name] is, you know, has to test herself four times a day...you know, and it's way way bigger than sort of her daily kind of routine, so...’ (P07).

Such comparison overall seemed to help mothers by providing context, and where risk was low this seemed to provide reassurance and normalised the situation.

What I wanted to know

The recommendations that participants made linked to their experiences and the ways in which they had understood and made sense of SUDEP. Mothers had ideas about when parents should be told, what kind of information should be provided and what form this could take. There was an acknowledgement that information on SUDEP was difficult to hear. Relatedly, there was a sense that mothers were trying to think of a point that was least emotionally difficult, while acknowledging this was hard to identify as there was no 'good' time to tell a parent. There was agreement across interviews that earlier was better:

‘...pick a moment that's not the worst time for them. Do you know, when – mebbe when their child is going through the worst bit....emmm...mebbe that might not be the time, mebbe they should tell you at the onset or something.’ (P01).

One participant felt that some parents might not want to know because of how difficult this could be and contrasted this to her own desire to know as much as possible:

‘...I know parents who don't want that information. They don't want to talk about the possibility of their kid dying. They don't want to talk about that, so (pause) it's hard to kind of put a...a pin in when it should be discussed because some parents are never going to want to have that conversation (pause). And then other parents are gonna want to know.’ (P02).

Although getting information on SUDEP could be difficult, it was often mentioned that parents should be told in case they came across the information in another way, echoing experiences where this had indeed been the case either online, via the media or other people:

'I think it is best that they kind of tell you, that they make you aware of it. Just so you are, so if you see or hear it some place you dinnae suddenly panic.' (P06).

Parents highlighted that information needed to be bespoke and understandable, depending on a parents' prior knowledge:

'I suppose somebody new, who'd never heard about epilepsy, and you'd not had anybody in the family, I would quite like to know, like, every single detail.' (P03).

Within this, information to be included often referenced wanting to know the specific likelihood of risk:

'...how can it happen and how many does it happen to, you know.' (P05).

Parents mentioned various ways that information could be provided, highlighting written information as important and suggesting ways this could be done:

'Maybe just not just oh, this is about SUDEP. Maybe give more general information all at the same time, so it's in there. But it's not just the one thing that you are saying to them' (P01).

'I don't know how you would do it, having some sort of folder – not like a manual because that's...having some sort of folder with so much information in it that you can pick and choose what you go through as things change in your life...and it's all labelled and if you don't want to read that section, then don't. Leave that section till you are ready...and then go back to your doctors and go like, OK, I've just read that chapter on that in the folder – so what exactly is that? Then they can go, right, she's asking the questions, now's the time to talk about it.' (P02).

'But maybe some like information posters or something, because I really haven't seen anything like that before you know.' (P10).

Finally, having time to discuss SUDEP with clinicians was emphasised:

‘I’d definitely liked to have sat down to discuss it, or maybe they give you the information and go back a couple of days later. When you’ve processed everything and, you know, you’ve written down what you need to ask so you don’t forget anything. Just, it would have been nice for a professional to tell you and have that reassurance.’ (P08).

This participant highlights the time parents may need to digest information, and the importance of asking questions. This opportunity was often seen as important not just directly after finding out, but throughout a child’s experience of epilepsy.

Discussion

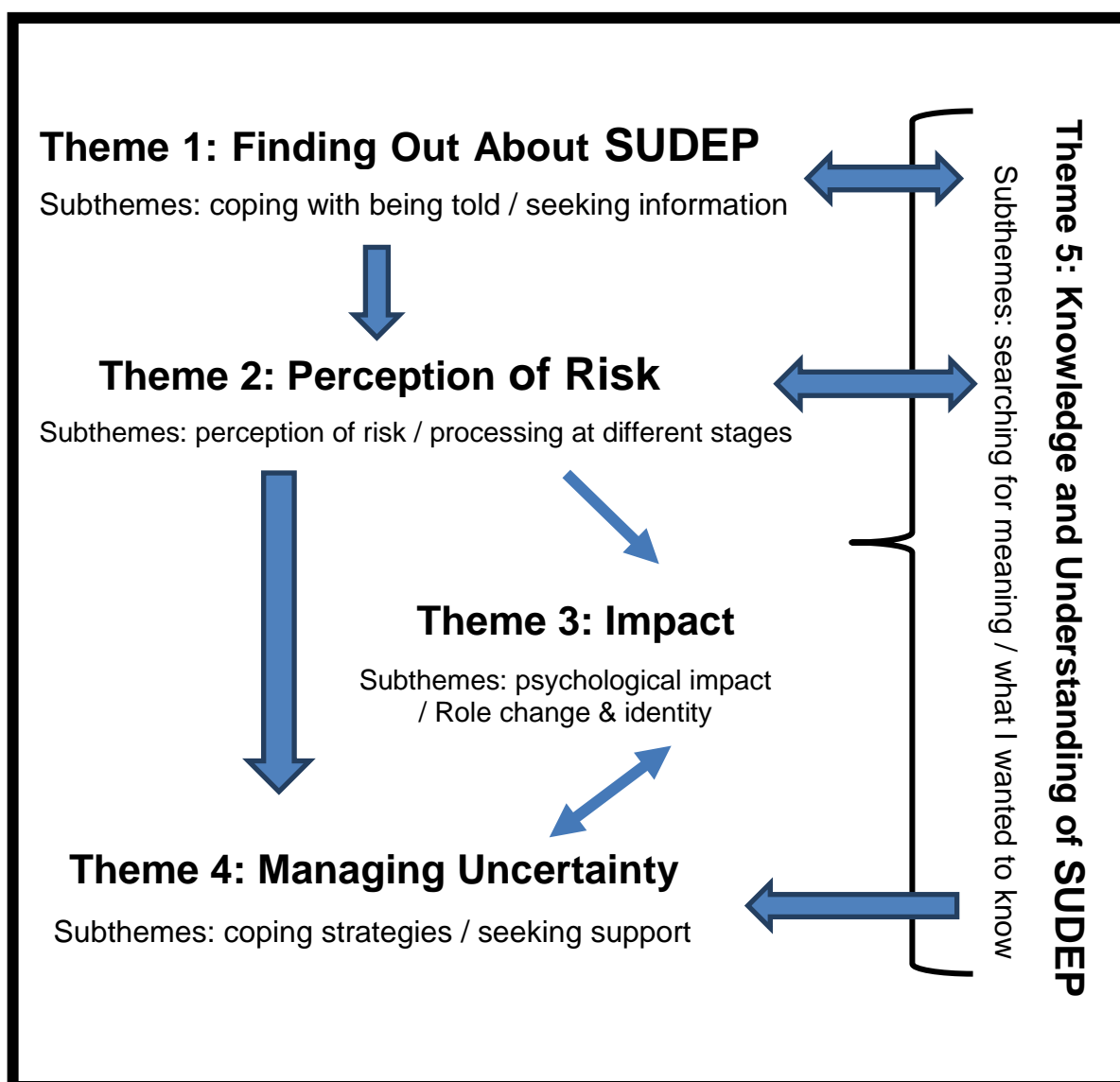
In reflecting across the interviews, overall it appeared that mothers were willing and keen to discuss their experiences. It was noticeable that some mothers were more willing to discuss the difficult aspects of understanding SUDEP, and this seemed to be reflected in their descriptions of their different ways of coping.

Finding out about SUDEP was significant for mothers in terms of its impact and effects. Knowledge and understanding of SUDEP changed over time. The experience of finding out about SUDEP seemed to be important in shaping a mother’s perception of risk to their child, their subsequent psychological responses and efforts to manage any uncertainty (see Figure 1 for a graphical representation of the links between themes). Participants received information about SUDEP in the context of their child being diagnosed with epilepsy. However, for some mothers, knowing about

SUDEP seemed to lead to experiences where risk was overestimated and was linked to anxiety, hypervigilance and cognitive coping strategies including avoidance. Overall, mothers described attempting to find meaning in, and increase their understanding of, SUDEP. Their recommendations of the ways clinicians can offer support regarding when, how and what information on SUDEP should be provided were clearly linked to their experiences, helpful and unhelpful.

Participants' experiences clearly link to health psychology research on uncertainty in illness, which has been defined as a cognitive state created when an illness related event cannot be adequately defined, categorised or predicted [45]. According to Mishel, there are four potential sources of uncertainty: ambiguity concerning the state of the illness, complexity regarding treatment, lack of information regarding the seriousness of the illness, and unpredictability regarding the course of illness [46]. In the present study, finding out about SUDEP often led to uncertainty regarding risk in relation to how much mothers initially understood and knew about SUDEP. Participants articulated ways in which finding out about SUDEP was overwhelming and led to fears of the worst-case scenario. Their understandable fear seemed to magnify and overestimate risk and this was exacerbated by a lack of information, difficulties in understanding complex medical information and information where risk was interpreted as being high. It is possible that this is in part due to the fact that SUDEP is not fully understood, with no means of eliminating the risk. Hence, uncertainty is always likely to be present to a lesser or greater extent.

Figure 1: Superordinate and subordinate themes and the relationships between them as presented in the interpretation.



Chronic uncertainty over health can be psychologically and socially toxic [47,48]. Perceived uncertainty has also consistently been found to be a major predictor of psychological distress in individuals with long-term conditions including diabetes and multiple sclerosis [49,50]. In addition, attributional style is implicated, namely the way in which parents made sense of SUDEP linked to their cognitive and behavioural coping responses. The concept of coping is a useful one as it places mothers' experiences in context. Coping is typically defined as adapting both cognitive and behavioural activity to manage demands that are appraised as taxing or exceeding personal resources [51]. This is considered to be a fluid process, where both the situation and the individual's perception of his or her own ability to cope, can change. As Lazarus and Folkman [51] recognise, there are limitations to this model. For example, when identifying a link between thoughts, coping and stress, there is a continual feedback loop between these variables which impact upon one another. Moreover, the idea of 'coping' is fairly broad, and therefore it is not always clear what 'coping' looks like [52].

Coping behaviours are commonly classified as being either problem- or emotion-focused [51]. Problem-focused coping involves generating solutions to solve the problem that is the cause of distress, and taking action by following through a plan. Strategies include learning a new skill or adjusting behaviour. Emotion-focused coping involves a reduction of the emotional distress by implementing strategies such as minimisation, avoidance or wishful thinking. Some coping strategies, such as seeking social support, may involve problem and emotion-focused functions simultaneously [53].

When applied to SUDEP, coping can be situated in the context of parental uncertainty. Where there was a greater risk of SUDEP, or a greater perceived risk, mothers seemed more likely to make efforts to manage their intolerance of uncertainty by working hard to 'solve the problem' of SUDEP by planning, pre-empting and information seeking.

A link between mothers' perception of risk and efforts to manage this seemed to emerge from the data. For mothers where the risk was higher (e.g. their child had a higher incidence of seizures), it was evident that interviews were characterised by their efforts to put in place measures to reduce the possible risk of SUDEP, for example the use of watches, sensors and other technologies (particularly used when children were sleeping). This also extended to their tendency to be hypervigilant, e.g. one participant who described giving up work to be with her daughter in case 'something happened'. Mothers also engaged in rumination about ways they could plan ahead to reduce risk. For those mothers where protective factors (e.g. prior familial experience of benign epilepsy) mitigated their perception of risk (e.g. P03), they didn't have the same sense of threat, and therefore did not need to manage this by using such measures nor seeking support.

Taylor [54] proposes a theory of cognitive adaption to threatening events where meaning is seen as an effort to understand an event, why it happened and the impact it has had in an attempt to answer the question, 'what is the significance of the event?'. In doing this, Taylor conceptualises meaning as understanding what life now means, gaining some kind of control over it and finding ways to feel good about oneself. There is a clear parallel with the results found in the present study.

In providing information on SUDEP, Nisbet [55] highlighted that medics may interpret a lack of response to difficult information as coping well. What the present study suggests is that it may also be due to feeling overwhelmed. This has a significant implication in how SUDEP information is provided. Mothers indicated that while it may be useful to tell parents about SUDEP at an early stage, there is a need to provide information across their child's contact with services. Furthermore, this information needs to be bespoke to an individual child's actual level of SUDEP risk, and provided in a way understandable to the parent in question. It may be that this is challenging within limited resources. This therefore may be helpful to incorporate into existing guidelines [17,18].

Future research

The findings from the present study indicate that mothers can have a strong emotional reaction to finding out about SUDEP. This is in line with prior research that parents in general may have an emotional response to this information (e.g. [22]). However, it has also highlighted the individual nature of the experiences of mothers. The results have highlighted research questions which warrant further investigation. One question is regarding the differences in parental experiences where children have more severe seizure disorders in comparison with those who experience seizures infrequently. The issues of uncertainty and a need to seek understanding of their child's condition may be experienced differently at different ends of this spectrum.

In addition, the present study interviewed mothers, therefore it would be informative to speak to fathers regarding their experiences to see if they are comparative. It may also be interesting to speak to parents as a couple (in families where both parents are present), as this relationship and the way in which parents 'work together' and influence each other may change responses to SUDEP. Finally, while IPA research has been conducted on neurologists' experiences of discussing SUDEP [55], it may also be helpful to explore the experience of nursing staff in discussing SUDEP with parents, particularly over time.

Strengths and limitations

There are some limitations with this study and methodology. Firstly, while IPA is a useful analytical process for developing complex and interrelated themes, these are specific to the accounts of the mothers included in this study and may not be representative of the general population of parents of children with epilepsy, especially as fathers were not included. Therefore, there may be other specific narratives for which access was not available. Participants did raise similar issues, and often with intensity, although their experiences and ways of coping were different. Hence, it is possible to make some cautious claims, particularly in relation to clinicians informing parents about SUDEP. In understanding mothers' experiences, clinicians clearly have a role in helping mothers make sense of their experiences in a helpful way, a way that is informed by understanding how parents may interpret risk and the potential psychological impact this can have.

Secondly, it is important to acknowledge the dynamic role of the researcher in both generating and analysing the data. In IPA, it is possible that another researcher with different personal characteristics, research background and theoretical beliefs would have facilitated a different discussion with participants, and a different interpretation of the data. This may in particular be relevant as the researcher has a background in clinical psychology work and was completing the project as part of doctoral training, and it is likely this had an impact on the way the interpretation was made (see Appendix P). As IPA maintains there is not one single account of the data, rather that there are potentially multiple accounts, this does not mean that any one account is incorrect, simply that each analysis is a unique interaction between researcher and participants. Also, it is possible that while the interview schedule had an intentionally open structure, it may have impacted on the issues that were raised.

Regarding strengths, the present review aimed to take a rigorous approach to conducting IPA. To meet this aim, an interview schedule was adhered to and included in the present article. In addition, elements of the research included having a second individual assessed the quality of two initial interviews to provide feedback on data collection. Importantly, detailed transparency regarding the impact of the researcher has also been included by providing reflective diary extracts from different stages of the process. Finally, details of the way in which analysis was carried out, and the inclusion of a sample coded interview, has been provided. It is hoped that these steps ensure a transparent account of the research process.

Conclusions

Mothers can experience finding out and knowing about SUDEP as psychologically distressing, prompting a search for meaning and knowledge. The perception of risk and attempts to manage uncertainty were important as mothers made sense of the information they received. The findings present a number of implications for clinical practice. Results highlighted that mothers want to be active and informed participants regarding SUDEP. Including them fully is likely to result in them feeling more empowered, possibly serving to reduce levels of parental distress and uncertainty [56]. It may also be that this assists in consistent treatment, which may limit SUDEP-related risk factors where possible. Recommendations for clinicians included informing parents about SUDEP as soon as possible, tailoring information to parents' existing knowledge, making information clear and making specific reference to the actual risk. This could perhaps be achieved by using comparisons and taking time to discuss any questions, which will probably help to minimise the likelihood of parents overestimating risk, and thus may decrease any distressing psychological impact.

Conflict of interest declaration

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Total Thesis Portfolio Word Count

20,722 words (including quotations, tables and citations).

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Research Ethics Service Approval**

**Appendix H: (ii) Empirical Article: Confirmation of Local Research and
Development Approval – NHS Tayside**

**Appendix H: (iii) Empirical Article: Confirmation of Local Research and
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DESCRIPTION

Seizure - European Journal of Epilepsy is an international journal owned by [Epilepsy Action](#) (the largest member led epilepsy organisation in the UK). It provides a forum for papers on all topics related to **epilepsy** and **seizure disorders**.

Seizure focuses especially on **clinical** and **psychosocial** aspects, but will publish papers on the basic sciences related to the condition itself, the differential diagnosis, natural history and epidemiology of **seizures**, as well as the investigation and practical management of seizure disorders (including drug treatment, neurosurgery and non-medical or behavioural treatments).

The journal reflects the social and psychological burden and impact of the condition on people with epilepsy, their families and society at large, and the methods and ideas that may help to alleviate the disability and stigma, which the condition may cause. The journal aims to share and disseminate knowledge between all disciplines that work in the field of epilepsy.

AUDIENCE

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GUIDE FOR AUTHORS

Your Paper Your Way

We now differentiate between the requirements for new and revised submissions. You may choose to submit your manuscript as a single Word or PDF file to be used in the refereeing process. Only when your paper is at the revision stage, will you be requested to put your paper in to a 'correct format' for acceptance and provide the items required for the publication of your article.

To find out more, please visit the Preparation section below.

INTRODUCTION

Types of articles

Seizure - European Journal of Epilepsy publishes the following types of article:

1.1 Peer-reviewed articles

a. Full reviews.

Seizure welcomes comprehensive reviews on all subjects relating to epilepsy and other seizure disorders. Authors planning/proposing are invited to discuss their ideas with Editor-in-Chief prior to submission. Full reviews should be preceded by an abstract. Full reviews should not exceed 7,000 words, include no more than 6 figures or tables and 150 references.

b. Focused reviews.

Seizure is keen to publish focused reviews, especially on the latest developments in particular fields or on topics which are currently debated by clinicians and researchers. Authors are welcome to approach the Editor-in-Chief with their idea for a focused review prior to submission. Focused reviews should be preceded by an abstract. Focused reviews should be 1,500-2,500 words, and include no more than 3 figures or tables and 50 references.

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The body of the text of these articles should be limited in length to 4,000 words, and there should be a maximum of 6 figures or tables. Additional figures, tables and other material (such as associated videos) can be submitted as online only Supporting Information (see section 'preparation of manuscripts' for further details). Full length research articles should be preceded by an abstract. The body of the text of the article should be clearly structured into 1) Introduction, 2) Methods 3) Results, 4) Discussion, 5) Conclusion and 6) References.

d. Short communications.

Comprise a number of different kinds of previously unpublished materials including short reports or small case series. Short communications should be preceded by an abstract. The body of the text is limited to 1,400 words. There are no more than 12 references, and 2 figures or tables (combined).

e. Case reports (Clinical Letters), see also *Interactive Case Insights* below

Seizure will also publish particularly instructive case reports in the format of Clinical Letters. Clinical Letters will not be preceded by an abstract. The word count is limited to 1,000 words. Clinical Letters can only include a maximum of 4 references and 2 figures or tables (combined), authors may include additional reading as supplementary material.

f. Letters to the Editor

Letters containing critical assessment of papers recently published in the *Seizure - European Journal of Epilepsy* will be considered for publication in the correspondence section. Letters should not exceed 1,000 words including references as necessary, one table or one figure. Letters should be typed in double spacing, should have a heading and no abbreviations. If related to a previously published article, the article should be identified by title, author(s), and volume/page numbers. All letters are subject to editorial review. At the Editor's discretion, a letter may be sent to authors of the original paper for comment, and both letter and reply may be published together.

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Other contributions than original research or review articles will be published at the discretion of the Editor-in-Chief, with only editorial review. Such material includes: obituaries, workshop reports and conference summaries, letters/commentary to the Editors (500 word limit, exceptionally including figures or tables), special (brief) reports from ILAE Commissions or other working groups, book reviews and announcements.

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The Editor-in-Chief invites ideas for supplements or special editions of *Seizure* including meeting abstracts. Such materials may be published, but only after prior arrangement with the Editor-in-Chief. Supplements will incur a charge. The page rate for proposed supplements can be negotiated with the Editor-in-Chief. Special editions are issues of *Seizure* wholly or partially dedicated to one particular topic. They may be edited or co-edited by internationally recognised experts in their field. Such experts do not need to be members of the Editorial Board of *Seizure* and are welcome to approach the Editor-in-Chief with their ideas. Special editions of *Seizure* would be expected to contain the same kind of manuscripts which are published in normal editions.

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Appendix B: Systematic Review: Example Database Search.















[My Account](#)
[Support & Training](#)
[Help](#)
 Logged in as Helen Galliard at University of Edinburgh
 [Logoff](#)
[Ask a Librarian](#)

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[Journals](#)
[Books](#)
[Multimedia](#)
[My Workspace](#)
[Amirsys](#)
[Mobile](#)


▼ Search History (12)

View Saved

<input type="checkbox"/>	# ▲	Searches	Results	Type	Actions	Annotations
<input type="checkbox"/>	1	(parent* or mother* or father).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]	689032	Advanced	Display Results More ▼	
<input type="checkbox"/>	2	epilep*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]	201750	Advanced	Display Results More ▼	
<input type="checkbox"/>	3	(experience* or understand* or opinion* or percep* or belie* or feel* or know* or qualitative).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word]	4603246	Advanced	Display Results More ▼	
<input type="checkbox"/>	4	exp PARENTS/	204447	Advanced	Display Results More ▼	
<input type="checkbox"/>	5	exp EPILEPSY/	197856	Advanced	Display Results More ▼	
<input type="checkbox"/>	6	exp QUALITATIVE RESEARCH/	45976	Advanced	Display Results More ▼	
<input type="checkbox"/>	7	1 or 4	710209	Advanced	Display Results More ▼	
<input type="checkbox"/>	8	2 or 5	224706	Advanced	Display Results More ▼	
<input type="checkbox"/>	9	3 or 6	4603272	Advanced	Display Results More ▼	
<input type="checkbox"/>	10	7 and 8 and 9	3027	Advanced	Display Results More ▼	
<input type="checkbox"/>	11	limit 10 to (english language and yr="1970 -Current")	2742	Advanced	Display Results More ▼	
<input type="checkbox"/>	12	remove duplicates from 11	2668	Advanced	Display Results More ▼	

Combine with:

[View Saved](#)


[Contract](#)

Appendix C: Systematic Review: Pre-1970 Search Results

Electronic databases CINAHL, PsychInfo, Medline, Embase and ASSIA were searched using the following search terms on 1st June 2018 with the limit that publication date was prior to 1970: parent* OR mother* OR father* AND epilep* AND interview* OR Experience* OR understand* OR opinion* OR percep* OR belie* OR feel* OR know* OR qualitative.. Deduplication was also included within these searches.

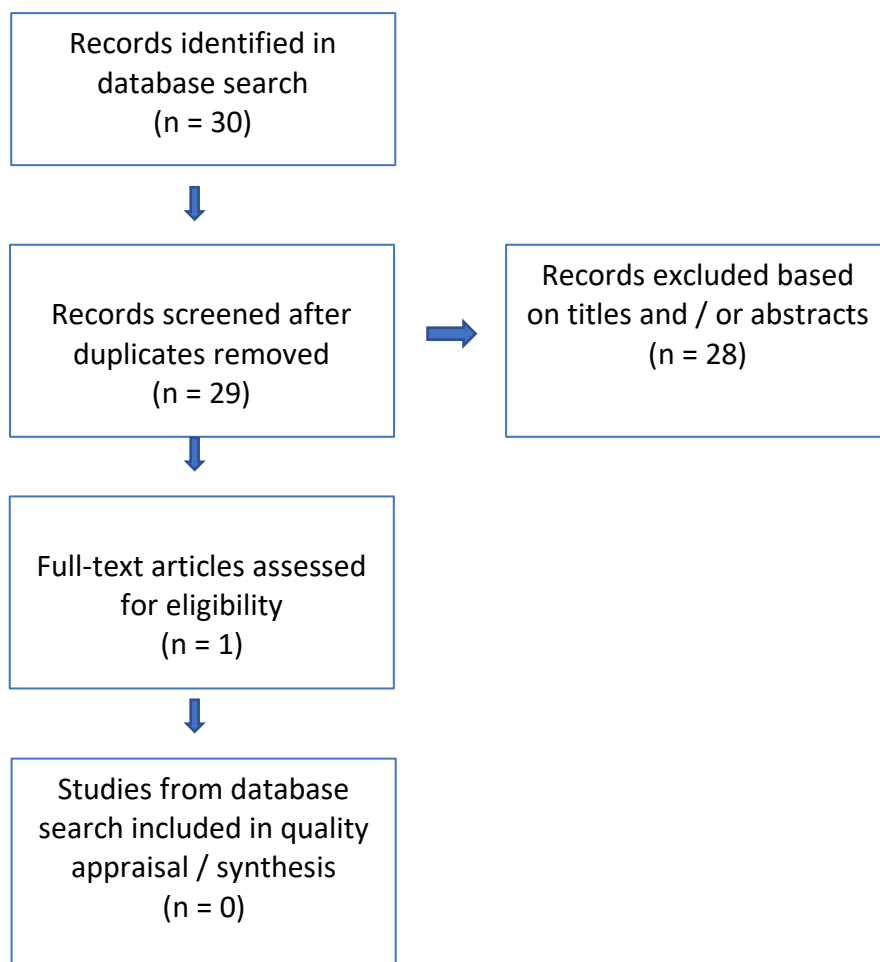
Search results screenshot (for CINAHL, Medline & PsychInfo search via Ovid):

The screenshot shows the Ovid search interface. At the top, there's a navigation bar with 'Search' highlighted. Below it, a 'Search History (3)' section lists three searches. Search 1 is a complex query: '((parent* or mother* or father) and epilep* and (experience* or understand* or opinion* or percep* or belie* or feel* or know* or qualitative)).af.' with 49,244 results. Search 2 is 'limit 1 to yr="1860 - 1970"' with 30 results. Search 3 is 'remove duplicates from 2' with 28 results. Below the history, there are buttons for 'Save', 'Remove', 'Combine with: AND OR', and 'Deduplicate'. At the bottom, there are buttons for 'Save All', 'Edit', 'Create RSS', and 'View Saved'.

#	Searches	Results	Type	Actions	Annotations
1	▶ ((parent* or mother* or father) and epilep* and (experience* or understand* or opinion* or percep* or belie* or feel* or know* or qualitative)).af.	49244	Advanced	Display Results More	
2	▶ limit 1 to yr="1860 - 1970"	30	Advanced	Display Results More	
3	▶ remove duplicates from 2	28	Advanced	Display Results More	

Note: Embase and Assia were searched separately, with 2 results being found via Embase (with 1 duplicate identified, and no search results being identified in Assia).

PRISMA flowchart showing appraisal of studies prior to 1970.



Appendix D: Systematic Review: References of Studies Excluded During Screening.

	Reference	Reason for Exclusion
1	Hames, A., Appleton, R. (2009) Living with a brother or sister with epilepsy: Siblings' experiences, <i>Seizure</i> , 18, 699-701.	Focused on children's experiences, not parent.
2	Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A. & Austin, J. (2016). The stigma experiences and perceptions of families living with epilepsy: Implications for epilepsy-related communication within and external to the family unit. <i>Patient Education & Counseling</i> , 99, 1473–1481.	Focused on communication within families, not experience of parents.
3	Gauffin, H., Flensner, G., Landtblom, A.-M., Landtblom, A.-M. (2015). Being parents with epilepsy: Thoughts on its consequences and difficulties affecting their children, <i>Neuropsychiatric Disease and Treatment</i> , 11, 1291-1298.	Focus on parents with epilepsy, not parents whose children have epilepsy.
4	Duffy, L. V. (2011). Parental coping and childhood epilepsy: The need for future research. <i>Journal of Neuroscience Nursing</i> , 43, 29–35.	Focus on interventions for facilitating coping in parents. Not parental experience.
5	Wagner, J. L., Sample, P. L., Ferguson, P. L., Pickelsimer, E. E., Smith, G. M., & Selassie, A. W. (2009). Impact of pediatric epilepsy: voices from a focus group and implications for public policy change. <i>Epilepsy & Behavior</i> , 16(1), 161–165.	Focus groups conducted with families, not just parents.
6	Amjad, R., Nikbakht Nasrabadi, A., & Navab, E. (2017). Family Stigma Associated With Epilepsy: A Qualitative Study. <i>Journal of Caring Sciences</i> , 6(1), 59–65.	Insufficient data available
7	Murray, J. (1993). Coping with the uncertainty of uncontrolled epilepsy. <i>Seizure</i> , 2(3), 167-178.	Insufficient data available.
8	Desnoux, B., Milh, M. & Auvin, S. (2012). Knowledges and beliefs of parents of children and adolescents with epilepsy. <i>Epilepsia</i> , 53, 84.	Insufficient data available.
9	Kampra, M., Siatouni, A., Verentzionti, A., Tzerakis, N., Androutsos, E. & Katsarou, E. (2012). School years for children with epilepsy in Greece: A voice coming from parents and children. <i>Epilepsia</i> , 53, 219.	Quantitative data.

10	Mbonda, P., Fogang, Y., Toffa, D., Ndiaye, M. & Diop, A. (2014). Family impact and parental perception of childhood epilepsy. <i>European Journal of Neurology</i> , 21, 88.	Quantitative data.
11	Jones, C., Atkinson, P., Memon, A., Gilliberg, K., Das, L., Dabydeen, L., Neville, B. & Scott, R. (2017). The experiences and needs of parents of children with early onset epilepsy: A population-based study. <i>Developmental Medicine and Child Neurology</i> , 59, 26.	Full text unavailable.
12	Carlson, J. & Miller, P. (2017). Family burden, child disability, and the adjustment of mothers caring for children with epilepsy: Role of social support and coping. <i>Epilepsy and Behavior</i> , 68, 168-173.	Quantitative data.
13	Anand, D., & Anand, R. (2014). Epilepsy and the child-parental coping and children's attitude. <i>Journal of Psychosocial Research</i> , 9, 33-44.	Focus groups conducted with families, not just parents.
14	Haddad, T. M. (2003). Parenting children with epilepsy: Challenges and methods of coping. <i>Dissertation Abstracts International Section A: Humanities and Social Sciences</i> . US: ProQuest Information & Learning.	PhD thesis, unpublished in a peer-reviewed journal.
15	Keikelame, M. J., & Swartz, L. (2007). Parents' understanding of the causes and management of their children's epilepsy in Khayelitsha, Cape Town. <i>South African Journal of Psychology</i> , 37, 307-315.	Not focused on parental experience of caregiving, but understanding / knowledge of causes of epilepsy.
16	O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A. & Austin, J. (2016). Talking about epilepsy: Challenges parents face when communicating with their child about epilepsy and epilepsy-related issues. <i>Epilepsy and Behavior</i> , 57, 9-15.	Focused on communication within families, not experience of parents.
17	Dardano, P. B. (2001). Mothers of children with epilepsy: Experiences and life goals. <i>Dissertation Abstracts International: Section B: The Sciences and Engineering</i> . US: ProQuest Information & Learning.	PhD thesis, unpublished in a peer-reviewed journal.
18	Harden, J. & R., B. (2016). Families' experiences of living with pediatric epilepsy: A qualitative systematic review. <i>Epilepsy and Behavior</i> .	Systematic review.
19	O'Toole, S., Benson, A., Lambert, V., Gallagher, P., Shahwan, A. & Austin, J. (2015). Family communication in	Systematic review.

	the context of pediatric epilepsy: A systematic review. <i>Epilepsy and Behavior</i> , 51, 225-239.	
20	Decker, K. A., Miller, W. R., & Buelow, J. M. (2016). Parent perceptions of family social supports in families with children with epilepsy. <i>Journal of Neuroscience Nursing</i> , 48(6), 336-341.	Quantitative data.
21	Amjad, R. & Navab, E. (2016). Parents of children with epilepsy captured by epilepsy: A qualitative study. <i>Acta Medica Mediterranea</i> , 32, 1303-1309.	Insufficient data available.
22	Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A. & Austin, J. (2015). To tell or not to tell: A systematic review of the disclosure practices of children living with epilepsy and their parents. <i>Epilepsy and Behavior</i> .	Systematic review.
23	Reed, M. P. (2013, January). Parental caregivers' description of caring for children with intractable epilepsy. Parental Caregivers' Description of Caring for Children With Intractable Epilepsy. Boston College.	PhD thesis, unpublished in a peer-reviewed journal.
24	Jones, J., Kessler-Jones, A., Thompson, M., Young, K., Anderson, A. & Strand, D. (2014). Zoning in on parents' needs: Understanding parents' perspectives in order to provide person-centred care. <i>Epilepsy and Behavior</i> , 37, 2014, 191-197.	Insufficient data available.



10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- **Are the results of the review valid?**
- **What are the results?**
- **Will the results help locally?**

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational tools as part of a workshop setting

There will not be time in the small groups to answer them all in detail!

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Screening Questions

1. Was there a clear statement of the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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2. Is a qualitative methodology appropriate?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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Is it worth continuing?



Detailed questions

3. Was the research design appropriate to address the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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4. Was the recruitment strategy appropriate to the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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5. Was the data collected in a way that addressed the research issue?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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6. Has the relationship between researcher and participants been adequately considered?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
 - (a) Formulation of the research questions
 - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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7. Have ethical issues been taken into consideration?

☐

Yes

☐

Can't tell

☐

No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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8. Was the data analysis sufficiently rigorous?

☐

Yes

☐

Can't tell

☐

No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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9. Is there a clear statement of findings?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Was the question:	Well addressed? <input type="checkbox"/>	Adequately Addressed? <input type="checkbox"/>	Not applied / reported <input type="checkbox"/>
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Appendix F: Example Coded Article from Thematic Synthesis.

Article: BENSON et al. (2017)	Initial Codes
<p><u>VERBATIM QUOTES (from Table 1):</u></p> <p>Theme 1: Seeking normalcy for the child</p> <p><i>Subtheme 1: Minimising the potential for different treatment</i></p> <p>“ . . .She said ‘no, you should tell people’, she said ‘because of. . .they’re aware’ and I said. . .’ he’s young and. . .I need to protect him. . .if there’s any chance that anyone out there is going to treat him any differently because of it. . .I am not going to tell them that. . .so. . . you can understand that when it’s your child. . . it’s a different thing than me as an adult having it and making that decision’ but I said ‘I have to look out for him’”</p> <p>“I’d be afraid he’d [referring to the child’s teacher] be kind of looking at him differently and treating him differently and watching and drama. . .calling me in and going ‘he looked sideways’. . .and I’m like ‘oh. No, that’s not. . .’ . . .so that’s. . .that’s my fear, people putting a different label on it or I-. . .labelling him-that’s my fear, yeah.”</p> <p><i>Subtheme 2: Avoiding the imposition of unnecessary restrictions</i></p> <p>“I mean the challenges, the risk of the potential of her being treated differently or to be looked on as someone who has got restrictions or stuff like that. So someone you would view as I don’t want to tell that person because I don’t believe that they would make the effort or they are open minded enough. And the worry about your life is what restrictions are going to be put in place. . .Whereas I just want to make sure there aren’t any restrictions for her. . . it is just the natural fear of the stigma. . .”</p> <p>“ . . .like. . .sport-wise. . .he wants to get on the top team. . .if you say too much. . .if you say he’s very poorly. . .they’re not going to put him on the team. You know, he did the wakeboarding nationals and he was going for gold. . .we said ‘do we say anything?’ and we didn’t this year. . .we said that we don’t need to tell anybody because. . .it could be, you know, they could go very gently on him then. .</p>	<p>Anticipating stigma</p> <p>Parent as advocate</p> <p>Anticipating stigma</p> <p>Anticipating stigma</p> <p>Anticipating stigma</p> <p>Worry for the future Lack of normalcy Fear of stigma</p> <p>Fear of limitations on child’s life</p> <p>Withholding information</p>

<p>.and I just felt no, just say nothing, let him do what he wants to do and we'll handle it if. . .if needs be. . ."</p> <p>Theme 2: the invisibility of epilepsy</p> <p><i>Subtheme 1: Silence around epilepsy</i></p> <p>"Well because I think that is something that is not in the public domain. I think it is not something that is talked about. I think people have very little awareness of it. People are very uncomfortable around it. I think it is a very complex one because there are very few people with a public profile who are open about having epilepsy. There are very few positive role models. And it is not something that comes up very often. I think in general it is something that people tend to cover up a lot."</p> <p>" . . .you hear about cystic fibrosis, you hear about diabetes, you hear about heart conditions, everything you turn on there is something or other, but epilepsy, not a lot when you think about it. I don't know when I heard the word last. It was the rugby coach talking about it. . .that was the last time I heard about it."</p> <p><i>Subtheme 2: Different to visible conditions</i></p> <p>" . . .I. . . it's a funny thing because, like, you know, kids that have, say, Cystic Fibrosis and other em. . . things. . . people seem to be able to talk about them more. . . I don't know what it is with the epilepsy. . . . it seems to be more hidden and. . . I don't think people understand it. . . you know? I don't know. . . or maybe because they haven't got a physical. . . deformity. . . to the. . . you know what I mean?"</p> <p>" . . . 'cause it's in the mind that it's kind of invisible. . . I mean. . . if you've a broken leg or if you have, god forbid, cancer or something like that, I guess it's more visible in terms of either they'd have a cast on or if you're going to chemotherapy you'll start to lose your hair. . . With something like epilepsy. . . you look absolutely perfect from the out- side. . . it's what goes on in the head and it's how it's manifested is so frightening. . . "</p> <p>Theme 3: Negative reactions to disclosure</p>	<p>Epilepsy is not talked about</p> <p>Lack of general knowledge</p> <p>Lack of examples in culture</p> <p>It's kept secret</p> <p>Comparison to other conditions</p> <p>Hidden disability</p> <p>Hidden disability</p> <p>Hidden disability</p> <p>Emotional impact</p> <p>Anticipating different treatment</p> <p>Contrast to normalcy</p> <p>Rejection from others</p>
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<p><i>Subtheme 1: Anticipated negative reactions</i></p> <p>“ . . . I have found. . . last year he got invited to a class party and I had to tell the woman. . . and I was actually dreading telling her. . . because I was afraid she wouldn't want him to go then. And then I said to myself, well, she's not going to say he can't go because of it but. . . I knew by the look on her face. . . she didn't really want to bring him. . . in case something. . . probably in case he had one. . . but she still brought him. . . but em. . . he wasn't asked the next year.”</p> <p>“ . . . I always, always, always qualify when I say Tom has epilepsy. . . I always say 'but it's not the one with the full-blown seizures', it's almost like I'm afraid I. . . because I believe people might be afraid of the full seizures because I was and I like to reassure people, which isn't right either”</p> <p><i>Subtheme 2: Actual negative reactions</i></p> <p>“We had trouble because she [referring to the child's school principal] wouldn't let Ruth take part in P.E. and...it was terrible, she would leave her in 3rd and 4th class doing her work She wanted a letter from the doctor. . . And it wasn't just that she was free to play. . . Everything had to be listed, she could skip, she could jump, she could play football, she could do this. It was a nightmare. Then Ruth took another seizure later on and Ruth begged me not to tell the teacher, and I didn't. For the simple reason that it was torture for the child. So I didn't.”</p> <p>“ . . . and the Scouts would have to be the worst case where we tried to enrol him in the local Scout troop. . . the first crowd we went to were bordering on the insulting in that, God he has got epilepsy. And one of them was in the background doing this [mimicking a seizure] to the other fellow as if to say, this is what we are signing ourselves up to with this guy. It shocked me. It is a national organisation, they probably get national money and they are excluding somebody for a medical reason.</p> <p>Theme 4: Contending with poor public perceptions of epilepsy</p> <p><i>Subtheme 1: Stigma</i></p> <p>“ . . . it's like a hidden thing or something. . . like. . .</p>	<p>Minimising the condition</p> <p>Negative response from others</p> <p>Emotional impact</p> <p>Emotional impact on child</p> <p>Stigma</p> <p>Exclusion</p> <p>Stigma</p> <p>Stigma</p>
--	--

<p>.like, I even find adults that have it don't like telling. . .talking about it. .I don't know whether it's the stigma attached from years ago because they thought people were. .manic, you know, when they had it, so. .I think it's there's a lot of stigma attached to it."</p>	Lack of understanding
<p>"Um. .well, where I come from. .um. .you know sometimes if you want to marry. .they do a research into your family. .and if you have something like that. .it's a no- no. .so. .um. .I'm not sure my kind of people are really aware of it. .or know what. .you know?. .You know, sometimes they even think it's contagious. ."</p>	<p>Fear</p> <p>Lack of knowledge</p>
<p>Subtheme 2: Lack of understanding</p> <p>Interviewer: "Is there anything that you would find challenging about talking to other people about Hannah's epilepsy?" Interviewee: "That they don't understand it. And then I don't know if I am explaining it properly although I know a good lot so far."</p>	Lack of knowledge
<p>"It is almost like there are different levels of. .well this is more ok than that is ok. I think that it all makes people feel so uncomfortable and people don't know what to do and people don't know how to react. . they are very frightened. .Then there are seizures that are less bad than other seizures. So what is challenging is that people basically know nothing about it."</p>	Containing emotional response
<p>"People have fairly simplistic views, I don't think people have any understanding of the breadth of the number of different types of seizures. They don't have any idea of how the side effects, the medication can impact or how tiring it can be."</p>	Emotional response
<p>Theme 5: Coming to terms with the diagnosis</p> <p>Subtheme 1: Maintaining composure</p>	Emotional response
<p>". .in the beginning I suppose I might have been slightly. .no, I wasn't even nervous. .I was probably more so. .em concerned about my reaction, that I'd hold it together when I was telling other people about it. .but at this stage it doesn't bother me. ."</p>	<p>Withholding information</p> <p>Minimising impact</p>
<p>"In the beginning I. .I must admit I found it very</p>	Emotional impact

<p>hard. I mean, I used to get very upset talking about it.”</p> <p>Subtheme 2: Private grief</p> <p>I’m a very private man. I . . . I keep myself to. . . I’m, I’m, I am a private man. . .”</p> <p>“Once she had the second one I just felt absolutely sick to the core and I actually couldn’t use the word, we didn’t tell anybody because I couldn’t articulate it for months. It was in November and we had the grandparents here for about a month at Christmas and at that stage she was having seizures left, right and centre. We never told them so we had this farcical situation where this child was on the floor in the hall having a seizure and we were kind of standing saying, ‘another cup of tea?’ It was utterly crazy really. But devastated, absolutely devastated. . .”</p> <p>“I didn’t want Tadhg to have epilepsy so I would have said Tadhg had encephalitis. . . I didn’t use, and for a long, long time I couldn’t spell the word epilepsy, I just had a mental block, I just couldn’t spell it. There was definitely a mental block there. Yes a bit of all of that, it is just not something I want my child to have.”</p> <p>Subtheme 3: Adjusting to changed hopes and expectations</p> <p>“ . . .at the beginning, like, when. . .when we found out. . .you just think you’re losing your mind [laughs]. . . it’s just, like. . .your whole world is just totally different. . . and I think it’s just your expectations for your child are totally different and. . .em. . . I don’t know, you don’t even know that you have an idea what their future is going to be like but you. . . obviously I did have an idea because now I’ve a totally different idea what his future’s going to be like or might be like em. . .”</p> <p>“Em. . . I think at the time, you know. . . you’re so horrifically shocked and devastated that your perfect child isn’t perfect and probably might never be totally perfect. . .”</p> <p>“Oh sure listen at 6 years of age Anna has epilepsy and I am thinking, oh my God she will never have a child, oh my God she will never get married, oh my</p>	<p>Psychological impact – avoidance</p> <p>Emotional impact</p> <p>Role changes</p> <p>Managing uncertainty</p> <p>Future concerns</p> <p>Emotional impact Loss of expected future</p> <p>Loss of expected future</p> <p>Emotional impact Change of expectations Loss of expected future Change in expectations</p> <p>Emotional impact Change in expectations</p> <p>Change in expectations</p> <p>Loss</p>
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God she will never go to college. . .sure, my other three children might never get married, they may never meet someone, they may never have a child. It never dawned on me for one second. But it was just this whole. . .everything came tumbling in together”

RESULTS SECTION

Seeking normalcy for the child

For many parents, seeking normalcy for their child was a priority. Numerous parents felt that they had a duty of care to protect their child from any threats to normalcy. Some parents referred to disclosure as challenging because they perceived others knowing about their child’s diagnosis as placing the child at risk of receiving different treatment and experiencing unnecessary restrictions. Consequently, parents viewed concealment and/or selective disclosure management strategies as beneficial in facilitating the pursuit of normalcy for their child and protecting their child’s psychosocial wellbeing. This was a particular concern for parents of younger children.

Minimising the potential for different treatment

A number of parents described striving to foster a sense of normality for their CWE by ensuring where possible that others did not treat or perceive the CWE differently because of his/her diagnosis. Some parents reported considering the perceived risk of disclosure resulting in consequences that would compromise this sense of normality, e.g., ‘drama’ arising, the CWE being ‘labelled’ or thought ‘less of’, or others viewing the diagnosis as infringing on the CWE’s ability to reach his/her “potential” and thus changing their treatment of the child. Among parents who perceived such risks existed, concealment and/or selective disclosure strategies were viewed as protective mechanisms to guard against such consequences.

Avoiding the imposition of unnecessary restrictions

Many parents emphasised the importance of their child availing of the same opportunities and partaking in the same activities as their peers, and/or continuing to pursue activities (e.g., competitive sports) they had engaged in prior to the epilepsy

Emotional impact

Parent as protector / role

Perceived stigma

Withholding diagnosis to protect child

Seeking normalcy

Perceived stigma

Loss of expected future
Limitations to child

Parent as protector (role)

Future concerns /
limitations

Normal activities

<p>diagnosis. Concealment and/or selective disclosure strategies were deemed desirable in instances where parents were concerned that life opportunities or participation in activities would be compromised due to the imposition of unnecessary restrictions on their child by others, if they were to learn of the diagnosis.</p>	<p>Concern about limitations in future</p> <p>Stigma / withholding diagnosis</p>
<p>The invisibility of epilepsy</p> <p>The invisible nature of epilepsy both in terms of how the condition is often not immediately physically apparent to others and the silence that surrounds the condition within the public arena acted as a deterrent to disclosure for many parents. Parents not only highlighted that epilepsy is not always overtly visible to others, but that the invisibility of the condition can be heightened by the scant attention epilepsy receives in the media and the reluctance of members of the public to broach and/or engage with the topic. Parents also made reference to dissimilarities between epilepsy and other 'more visible' conditions, commenting on how these conditions are viewed more favourably than epilepsy. The invisibility of epilepsy encouraged some parents to conceal and/or selectively disclose their child's epilepsy diagnosis.</p>	<p>Hidden disability</p> <p>Potential stigma</p> <p>Lack of public knowledge</p> <p>Negative comparison to other conditions</p> <p>Withholding diagnosis</p>
<p>Silence around epilepsy</p> <p>Parents felt epilepsy was invisible within the public domain. They believed that there was a lack of dialogue about epilepsy, it received limited media attention and few public figures advocated for it. Parents thought this silent message, reflective of how epilepsy is perceived by society, was not a positive one. It suggested to them that others were uncomfortable with and fearful of epilepsy. This caused reluctance among several parents to disclose their child's epilepsy diagnosis to others.</p>	<p>Hidden disability</p> <p>Lack of knowledge / discussion</p> <p>Stigma</p> <p>Withholding diagnosis</p>
<p>Different to visible conditions</p> <p>A number of parents made comparisons between epilepsy and other chronic conditions (e.g., cancer, cystic fibrosis, eczema) they perceived to be more visible due to their physical manifestations, reporting that such conditions are less 'hidden', have fewer negative connotations, and receive more attention within a public forum. This heightened the feeling amongst parents that epilepsy is a stigmatised condition, thus promoting parental silence surrounding the condition. Some parents also</p>	<p>Comparison to other conditions</p> <p>Stigma</p> <p>Withholding</p>

<p>referred to how in comparison with the seemingly innocuous physical manifestations of many other more visible, chronic conditions, when the symptoms of epilepsy do physically manifest, they can be intrusive, startling, fear-evoking and distressing to witness. Among these parents, if the child's epilepsy was well controlled or if seizures occurred only within the confines of their home (e.g., nocturnal seizures), some chose concealment and/or selective disclosure strategies to avoid experiencing negative reactions from others.</p>	<p>Fear</p> <p>Withholding diagnosis for fear of negative reactions</p>
<p><i>Negative reactions to disclosure</i> Fear of negative responses, as well as actual experiences of negative reactions by others to past parental disclosures of the children with epilepsy's (CWE's) diagnosis, presented challenges for some parents. In instances where parents perceived that there was a risk that others would respond negatively, or indeed when they and/or their child had suffered negative ramifications as a result of previous disclosure exchanges about the child's epilepsy diagnosis, parents tended to either maintain secrecy around the child's diagnosis or be selective in disclosure targets (i.e., to whom they would disclose) and content (i.e., what aspects of the diagnosis they would discuss).</p>	<p>Fear of negative reactions</p> <p>Actual negative reactions</p> <p>Stigma leads to withholding diagnosis</p>
<p><i>Anticipated negative reactions</i> Some parents relayed fearing that subsequent to disclosure of the CWE's diagnosis they and/or their child would be subjected to stigmatisation, prejudiced attitudes, discrimination, and/or exclusion from social, recreational and/or sporting activities. In particular, a number of parents alluded to being apprehensive about how parents of their child's peers would respond and whether this would limit future invitations to playdates, parties and sleepovers, and consequently negatively impact on their child's friendships and socialisation.</p>	<p>Feared stigma from others</p> <p>Feared stigma from peers</p> <p>Feared social isolation</p>
<p><i>Actual negative reactions</i> A number of parents reported how prior disclosure exchanges had resulted in negative consequences for them and/or their child. For some families, parental disclosure had resulted in the CWE receiving fewer invitations to social occasions, being excluded from participating in physical education in school or being denied enrolment in recreational activities. Detrimental impacts for parents included</p>	<p>Actual stigma form others</p> <p>Social isolation</p> <p>Limitations to child's life</p>

<p>offensive reactions, e.g., others mimicking seizures, and difficulty finding someone to care for the child in their absence. These experiences elicited negative emotions among parents (e.g., anger, concern, sadness, disappointment) and played a role in promoting parental disclosure decisions of concealment or selective disclosure.</p> <p>Contending with poor public perceptions of epilepsy Several parents believed public perceptions of epilepsy were poor. Some parents felt that epilepsy is a condition that is stigmatised and others made reference to the dearth of knowledge and understanding about epilepsy among the general population. Parents asserted that negative perceptions of epilepsy were difficult to contend with and contributed to their reluctance to disclose their CWE's diagnosis to others.</p> <p>Stigma Some parents alluded to the stigma surrounding epilepsy, likening it to the stigma that encircles mental illness. Many parents discussed how, to their dismay, they felt that antiquated misconceptions of epilepsy persisted in modern day society, e.g., the notion of epilepsy as contagious and associated with mania and witchcraft. Parents highlighted how epilepsy-related stigma manifests itself in others as fear and/or discomfort. For one family, this stigma seemed to be more profoundly felt due to culture dictating that epilepsy is not something that is acceptable (parents of Nigerian origin/descent). Concealment and/or selective disclosure management strategies were preferred by families who perceived epilepsy-related stigma as problematic.</p> <p>Lack of understanding Lack of public understanding and knowledge regarding what epilepsy is, the various presentation of seizures and what epileptic syndromes encompass (i.e., the physical, cognitive, and psychosocial consequences of epilepsy) inhibited parental openness about their child's epilepsy. Stereotypes, common misconceptions and the complexity and heterogeneity of the condition exacerbated this lack of understanding by others. Additionally, several parents reported that a perceived lack of desire from others to engage in</p>	<p>Negative reactions from others</p> <p>Emotional responses</p> <p>Withholding the diagnosis</p> <p>Poor public perception of epilepsy</p> <p>Lack of knowledge</p> <p>Stigma / withholding diagnosis</p> <p>Stigma</p> <p>Misunderstanding</p> <p>Others – fear</p> <p>Perception due to cultural norms</p> <p>Withholding diagnosis due to stigma</p> <p>Lack of knowledge – public</p> <p>Withholding diagnosis</p> <p>Lack of understanding about epilepsy</p>
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<p>discussion and learn about the child's epilepsy fostered their unwillingness to disclose.</p> <p><i>Coming to terms with the diagnosis</i> For many parents on receiving the diagnosis of their child's epilepsy, a period of grief ensued as parents grappled with the loss of their 'healthy child'. Many parents verbalised that the diagnosis had a profound emotional impact, evoking 'devastation', 'upset', 'concern', 'worry' and 'shock'. Parents reported struggling to maintain composure when speaking with others about their child's diagnosis. Parents also spoke about the need for time and space to privately grieve the loss of their 'healthy child'. Furthermore, parents expressed difficulties with adjusting their hopes and expectations for their child due to the epilepsy diagnosis. During this period of parental struggle (which varied considerably in length across families), many parents reported that disclosure was problematic. They consequently adopted concealment and/or selective disclosure management strategies.</p> <p><i>Maintaining composure</i> A number of parents relayed how speaking with others about their child's epilepsy diagnosis elicited tangible evidence of upset (i.e., 'tears', a 'wobble in [their] voice' and 'crying'). Several parents verbalised their discomfort with others witnessing them in this emotionally vulnerable state and their felt need to 'hold it together' when disclosing their child's diagnosis to others. Notwithstanding this, maintaining composure when speaking to others about their child's diagnosis was difficult for many parents, particularly in the time-period immediately post-diagnosis. Consequently, several parents adopted concealment or selective disclosure strategies to avoid public emotional displays.</p> <p><i>Private grief</i> Many parents relayed that following receipt of their child's epilepsy diagnosis, they embarked on a period of mourning for the loss of their 'healthy child'. A number of parents reported needing time and space to grieve privately, and to process and come to terms with the diagnosis before they were capable of speaking about it with others. How families processed this grief varied significantly across families, dependent on a number of situational factors. Some parents felt that they possessed</p>	<p>Lack of willingness to learn about epilepsy linked to withholding diagnosis</p> <p>Loss of expected future – grief Finding out – emotionally difficult</p> <p>Processing diagnosis over time</p> <p>Adjusting to the diagnosis</p> <p>Withholding diagnosis – emotional impact</p> <p>Emotional responses</p> <p>Containing / withholding emotions</p> <p>Maintaining composure</p> <p>Diagnosis as emotionally difficult.</p> <p>Withholding – strategy to manage emotions</p> <p>Loss of expected future Time to process diagnosis</p> <p>Various coping strategies</p>
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personality traits that heightened their reluctance to disclose their child's diagnosis. For instance, parents who perceived themselves as 'private' by disposition, or parents who expressed their preference to 'suffer in silence' rather than seek help and support from others, were less likely to disclose their child's diagnosis to others during this grieving period. Some parents reported that coming to terms with their child's epilepsy diagnosis was a difficult and lengthy process because it had come as a complete shock to them ('how did this happen?', 'when I was pregnant with her I did everything right') or because they had negative perceptions of epilepsy themselves ('because I believe people might be afraid of the full seizures, because I was'). A number of parents engaged in denial as a coping mechanism in the initial period following their child's epilepsy diagnosis. In this context, disclosure was extremely challenging.

Adjusting to changed hopes and expectations

Several parents recounted how their child's epilepsy diagnosis had dashed and/or altered pre-conceived hopes and expectations they had held (at times unwittingly) for the future of their child. Particularly, in the initial stages post-diagnosis, parents perceived that their child's academic, occupational, romantic and/or social potential would be limited due to his/her epilepsy. During this initial period of adjustment, the prospect of disclosing their child's diagnosis to others was difficult as it elicited emotions of concern, worry and upset.

Suffer in silence
Withhold diagnosis
Not seeking help

Shock of finding out

Denial / avoidance – coping strategy at diagnosis

Loss of expected future

Limitations to child.

Emotional / psychological impact.



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Epilepsy & Behavior is the fastest-growing international journal uniquely devoted to the rapid dissemination of the most current information available on the behavioral aspects of seizures and epilepsy.

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6 December 2016

Dr Ailsa McLellan
Edinburgh Sick Children's Hospital
9 Sciennes Road
Edinburgh
EH9 1LF

Research & Development
Room E1.12
Tel: 0131 242 3330

Email:
accord@nhslothian.scot.nhs.uk

Director: Professor David E Newby

Dear Dr McLellan

Lothian R&D Project No: 2016/0298

REC No: 16/ES/0133

Title of Research: Providing information about the risk of sudden death in epilepsy (SUDEP) in children: what are the effects on parents?

Participant Information Sheet:
Version 3.0, dated 27 November 2016

Consent Form:
Version 3.0, dated 27 November 2016

Protocol: Version 1.0, dated 7 October 2016

I am pleased to inform you this letter provides Site Specific approval for NHS Lothian for the above study and you may proceed with your research, subject to the conditions below.

Please note that the NHS Lothian R&D Office must be informed of any changes to the study such as amendments to the protocol, funding, recruitment, personnel or resource input required of NHS Lothian.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please keep this office informed of the following study information:

1. Date you are ready to begin recruitment, date of the recruitment of the first participant and the quarterly recruitment figures thereafter.
2. Date the final participant is recruited and the final recruitment figures.
3. Date your study / trial is completed within NHS Lothian.

I wish you every success with your study.

Yours sincerely

Ms Fiona McArdle
Deputy R&D Director

CC: Ms Helen Galliard, Trainee Clinical Psychologist, NHS Tayside

02 December 2016

Dr Martin R Kirkpatrick
Department of Paediatrics
Ninewells Hospital and Medical School
DUNDEE
DD1 9SY

Dear Dr Kirkpatrick,

R&D MANAGEMENT APPROVAL – TAYSIDE

Title: Providing information about the risk of sudden death in epilepsy (SUDEP) in children: what are the effects on parents?

Chief Investigator: Ms Helen Galliard

Principal Investigator/Local Collaborator: Dr Martin Kirkpatrick

Tayside Ref: 2016PZ08 NRS Ref: NRS16/214894

REC Ref:16/ES/0133

Sponsor: University of Edinburgh

Funder: No external funding

Many thanks for your application to carry out the above project here in NHS Tayside. I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for the study to proceed locally in Tayside.

Approval is granted on the following conditions:-

- ALL Research must be carried out in compliance with the Research Governance Framework for Health & Community Care, Health & Safety Regulations, data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).
- All amendments to be notified to TASC R&D Office via the correct amendment pathway. Either direct to the R&D Office or via the Lead Co-ordinating Centre depending on how the study is set up (<http://www.hra.nhs.uk/nhshsc-rd-uk-process-management-amendments/>).
- All local researchers must hold either a Substantive Contract, Honorary Research Contract, Honorary Clinical Contract or Letter of Access with NHS Tayside where required (<http://www.nihr.ac.uk/policy-and-standards/research-passports.htm>).
- TASC R&D Office to be informed of change in Principal Investigator, Chief Investigator or any additional research personnel locally.
- Notification to TASC R&D Office of any change in funding.

- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until destruction of this data.
- All eligible and adopted studies will be added to the Central Portfolio Management System (CPMS) <https://cpms.nihr.ac.uk>. Recruitment figures for eligible and adopted studies must be recorded onto the Portfolio every month. This is the responsibility of the lead UK site. If you are the lead, or only UK site, we can provide help or advice with this. For information, contact Sarah Kennedy (01382 383882 or sarah.kennedy17@nhs.net) or Margaret Marshall (01382 383091 or margaret.marshall7@nhs.net).
- Annual reports are required to be submitted to TASC R&D Office with the first report due 12 months from date of issue of this management approval letter and at yearly intervals until completion of the study.
- Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R&D Office.
- You may be required to assist with and provide information in regard to audit and monitoring of study.

Please note you are required to adhere to the conditions, if not, NHS management approval may be withdrawn for the study.

Approved Documents

Document	Version	Date
IRAS R&D		
IRAS SSI		
Protocol	V1	06/10/16
Cover letter	1	06/10/16
Letter of invitation	2	11/11/16
Consent	3	27/11/16
PIS	3	27/11/16
Draft interview schedule	1	06/10/16
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CV – Kenneth Macmahon		
CV – Dr Aileen McCafferty		
REC provisional opinion		31/10/16
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May I take this opportunity to wish you every success with your project.

Please do not hesitate to contact TASC R&D Office should you require further assistance.

Yours sincerely

Elizabeth Coote
Head of Non-Commercial Research Services

TAyside medical Science Centre (TASC)
Ninewells Hospital & Medical School
TASC Research & Development Office
Residency Block, Level 3
George Pirie Way
Dundee DD1 9SY
Email: liz.coote@nhs.net
Tel: 01382 383876 Fax: 01382 740122

c.c. Helen Galliard
 Laura Stephen
 TASC Feasibility Team

Tayside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Ms Helen Galliard
Trainee Clinical Psychologist
NHS Tayside
15 Dudhope Terrace
Dundee
DD3 6HH

Date: 22 November 2016
Your Ref:
Our Ref: LR/16/ES/0133
Enquiries to: Mrs Lorraine Reilly
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Ms Galliard

Study Title: Providing information about the risk of sudden death in epilepsy (SUDEP) in children: what are the effects on parents?
REC reference: 16/ES/0133
IRAS project ID: 214894

Thank you for your letter of 18 November 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Lorraine Reilly, eosres.tayside@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with

updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

- The Committee has requested that more information is inserted in the PIS regarding the support available if participants become distressed (i.e. what experience the research has for dealing with this type of situation and inform participants that they can contact their Epilepsy nurse after the interview should they need to).

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise). Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper [Further Information]		18 November 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional indemnity]		25 July 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Clinical Trial Liability]		25 July 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		21 July 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
Interview schedules or topic guides for participants [Draft Interview Schedule]	1	06 October 2016
IRAS Checklist XML [Checklist_18112016]		18 November 2016
Letters of invitation to participant [Cover Letter]	1	06 October 2016
Other [Letter of Invitation]	2	11 November 2016
Participant consent form	2	18 November 2016
Participant information sheet (PIS) [Participant Information Sheet]	2	11 November 2016
REC Application Form [REC_Form_07102016]		07 October 2016
Research protocol or project proposal [Protocol]	1	07 October 2016
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		
Summary CV for supervisor (student research) [Academic Supervisor CV]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/ES/0133

Please quote this number on all correspondence

Yours sincerely

pp
Dr Robert Rea
Chair

Email: eosres.tayside@nhs.net

Enclosures: “After ethical review – guidance for researchers”

Copy to: Ms Charlotte Smith, University of Edinburgh
NHS Tayside R&D



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Risk in SUDEP: Parental Experiences / Version 2 / Date: 11/11/2016

APPENDIX I: Letter of Invitation to Participate

Dear Madam,

RE: Providing information about the risk of sudden death in epilepsy (SUDEP) in children: what are the effects on parents?

My name is [Researcher] and I am a Trainee Clinical Psychologist, studying at the University of Edinburgh and working in the Tayside Clinical Psychology Department (Child and Adolescent Mental Health Service).

I write to invite you to take part in a study which I am conducting as part of my training in NHS Tayside. I am interested in the experience of mothers whose child has been diagnosed with epilepsy and who have been told about the risk to their child of sudden unexpected death in epilepsy (SUDEP) and the impact this had on the parent of a child with epilepsy. It is hoped that this information will help the relevant services gain a better understanding of what it is like for a parent to receive information about SUDEP following their child being diagnosed with epilepsy, and to ensure that appropriate information and support is given to them.

As you are the parent of a child with epilepsy, I am interested in your experience and views on this experience.

If you decide to participate, you would be required to be interviewed (by myself). This interview would take no more than 1 hour and would be audio-recorded. The recordings would then be transcribed into print. The information you would give would be anonymised in any report (you nor your child would be identifiable).

Please find enclosed some further information about the study. Please take the time to read the information and consider whether you wish to take part. You may discuss this information with your friends and family if you wish.

If you would like to find out more about the study or are interested in taking part, please contact me on 01382 366 565. If you decide to participate I will arrange a meeting with you to discuss the study further and arrange an interview time.

Thank you for your time,

Yours faithfully,

Trainee Clinical Psychologist

Clinical Psychologist

APPENDIX J: Participant Information Sheet

What is the impact on mothers of being told about their child's risk of sudden death in epilepsy (SUDEP)?

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Please contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Sudden Unexpected Death in Epilepsy (SUDEP) describes death in someone with epilepsy that cannot be explained. It is recommended that information about SUDEP is discussed with parents of children with epilepsy; however, little is known about the experience of parents reacting to and processing this information. In particular, there is not much research on parent's experiences of being told about SUDEP, the emotional impact nor any effect on parent's behaviour towards their child.

Mothers identified by paediatric neurology services within two NHS health boards will be asked to participate in the study. Mothers are being asked to keep participants as similar as possible, future research may investigate father's responses. Interviews will be conducted with mothers who have talked to their child's paediatrician about the risk of SUDEP. The interviews will aim to gain in-depth understanding of the psychological impact of SUDEP discussions. This may include changes in anxiety levels, parenting behaviours or interactions with their child.

This study hopes to gain a better understanding of how best to discuss the risk of SUDEP with parents. Interview transcripts will be analysed to look at the psychological impact of finding out about SUDEP. By understanding more about your experiences, it may help to inform how information provision can be tailored more appropriately will ideally enhance understanding of providing information on SUDEP and help to limit emotional distress.



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Risk in SUDEP: Parental Experiences
Version Number: Version no. 3. Date 27/11/2016

Why have I been asked to take part?

You have been asked to take part as your child has been previously diagnosed with epilepsy and you attend regular routine epilepsy clinics.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you or your child receives, or your legal rights.

What will happen if I take part?

Your child's Consultant Paediatric Neurologist will have identified you as a possible participant and provided you with this initial information. If you are interested in finding out more, your Neurologist will then ask you to fill out a contact information form. This form will be given to the Researcher who will contact you in your preferred way, either via telephone, e-mail or letter. Participants who received the study information will be given a minimum of 24 hours before being contacted by the researcher to ask whether they would be interested in taking part in the study. This initial contact will give you the opportunity to ask any questions you may have, but does not mean that you have consented to take part on the study.

If you are still interested in taking part in the study following this initial contact, a suitable time to meet for a face-to-face meeting will be arranged with the Researcher. At this meeting, you can find out more about the study, ask any questions and if you still want to participate, you will be asked to provide your formal consent.

Following consent, you will be asked to attend an interview that will be between 30 and 60 minutes long, where the Researcher will ask you about your experience of being told about the risk of SUDEP. Interviews will primarily be done in person either at an NHS location or at your home, but



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may be done via Skype if required. While Skype is a new medium for data gathering, it has been used successfully in research and has been evaluated as a suitable research tool.

The interview will be audio recorded and following the interview, the Researcher will transcribe the content in order to then explore the information provided in detail. Once interviews have been transcribed, data cannot be removed should participants withdraw from the study. Any personal identifiable information (names, places etc.) will be removed from the transcripts.

Once all interviews with all participants have been completed, the Researcher will analyse the interviews for common themes and will write up the findings.

In this type of research, direct quotations from participants are often used when writing up the work. They help to illustrate what participants have spoken about. Any quotations will be entirely anonymous and will not use any information that might identify individuals.

What are the possible benefits of taking part?

You may not get a direct benefit from taking part in this study, although it may be of great benefit to parents being informed about the risk of SUDEP to their child in the future.

What are the possible disadvantages and risks of taking part?

It is not thought that there are many disadvantages, however, it is possible that due to the subject material, some emotional distress may be experienced by participants. If this does happen, support will be provided.

The researcher has experience as a 2nd year Trainee Clinical Psychologist, and as a trained Clinical Associate in Applied Psychology; accordingly, has worked in a clinical capacity for over 4 years supporting people in distress, including those experiencing mild to moderate distress as well as those expressing suicidal ideation. For those who may potentially experience distress during the interview process, my psychological training will allow me to support participants directly if and when distress arises.



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Participants will be told that they can request that an interview stops so they can take a break, or end the interview, if they feel distressed. Alternatively, participants will have the ability to contact their Epilepsy Specialist Nurse, who can also provide emotional support if required and on an ongoing basis. In addition, any significant mental health concerns would include a discussion about accessing other services, e.g. local adult mental health services accessible via their GP.

In addition, it may be that time is required in order to travel to and attend meetings and interviews. However, travel expenses will be reimbursed by NHS Tayside and there will also be the option to have the Researcher meet you at home to minimise these difficulties.

What if I have any questions?

If you have a concern about any aspect of this study, please contact the Researcher who will do their best to answer your questions.

What happens when the study is finished?

The study will be written up as a PhD thesis and presented to the NHS Tayside Psychological Therapies Department. You will not be identifiable in any published results. If participants wish to be sent the project results, they can contact the Researcher. At the end of the research we will retain anonymous data for 3 years.

Will my taking part in the study be kept confidential?

The Researcher will obtain some general information about your child's seizure disorder (including type of epilepsy, age at diagnosis, number / type of medications). All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

To ensure that the study is being run correctly, we will ask your consent for responsible representatives from the Sponsor and NHS Institution to access your data collected during the study, where it is relevant to you taking part in this research. The Sponsor is responsible for overall management of the study and providing insurance and indemnity.



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What will happen to the results of the study?

The study will be written up as a Doctorate in Clinical Psychology thesis and presented to the NHS Tayside Psychological Therapies Department. You will not be identifiable in any published results. If participants wish to be sent the project results, they can contact the Researcher.

Who is organising the research and why?

The study is being completed as part of the Researcher's Doctorate in Clinical Psychology at Edinburgh University. This study has been sponsored by the University of Edinburgh and funded by NHS Tayside.

Who has reviewed the study?

The study proposal has been reviewed by the University of Edinburgh. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from NHS Tayside REC. NHS management approval has also been obtained.

The East of Scotland Research Ethics Service REC 1, which has responsibility for scrutinising all proposals for research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from NHS Tayside, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

If you have any further questions about the study, please contact Helen Galliard on:

Telephone: 01382 346 565 or email: helen.galliard@nhs.net

If you would like to discuss this study with someone independent of the study, please contact: [contact details]

If you wish to make a complaint about the study, please contact the University of Edinburgh's Research Governance team via email at: resgov@accord.scot

Thank you for taking the time to read this information sheet.



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Risk in SUDEP: Parental Experiences
Version number: Version 3. Date: 27/11/2016

APPENDIX K: CONSENT FORM

Risk in SUDEP: Parental Experiences

Participant ID:

[Please insert contact details of person taking consent]

Please initial box

1. I confirm that I have read and understand the information sheet (Version 3, Date: 27th November 2016) for the above study and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of data collected during the study may be looked at by regulatory authorities and from the Sponsor (NHS Lothian and the University of Edinburgh) or from the other NHS Boards where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that audio recordings of the interview will be made and transcribed and agree to direct quotations from the interview can be included in the final research report. ☐
5. I agree to take part in the above study. ☐
6. I would like to be sent a copy of the results of the study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Date: 27/11/16

APPENDIX L: Demographic Information

What is the age of your child?.....

.....

What is the gender of your child?.....

.....

What age was your child diagnosed with epilepsy?.....

.....

What type of seizure disorder has your child been diagnosed with?.....

.....

What number of epilepsy medications does your child take currently?.....

.....

Does your child have any other diagnoses (e.g. developmental disorder).....

.....

What number of seizures does your child have?

Less than 1 a month	
1 or more a month	
1 or more a week	
1 or more a day	
other? (multiple in a row / unusual pattern)	

APPENDIX M: Interview Schedule

The headings indicate the areas for exploration. Prompts are general, for example 'Can you tell me more about that...'. The bold text indicates the primary questions to be asked, with the other questions as possible prompts.

1. Information Sharing Experience

Interview Question: Can you tell me what you remember about the experience of being told about SUDEP?

Who, where, what?

2. Short-Term Impact

Interview Question: What was this like for you?

Emotionally, physically, what did you think, what went through your mind? How did you feel about it later that day / week etc.? Did you talk about it with anyone? Did you look for additional information? If so, from where, who?

3. Longer-Term Impact

Interview Question: Did it affect your relationship with your child?

Parenting behaviour? Other relationships? Were you aware of any impact on your child?

4. Advice

Interview Question: What should clinicians tell parents about SUDEP?

Is there any information you would have liked to have been told? Anything you wouldn't have liked to have been told? Do you have any recommendations to clinicians? Anything they could do differently?

APPENDIX N: Empirical Article: Coded Interview

Interview 10 – 4th July 2017

Interview Duration: 23 minutes 39 seconds.

Location: Participant's home.

I: Interviewer

P: Participant

H: Participant's child's name, anonymised.

A: participant's other child.

ORIGINAL TRANSCRIPT

EXPLORATORY COMMENTS

EMERGENT THEMES

Descriptive comments: Roman text.
Linguistic comments: *Italic text*.
Conceptual: Underlined text.

I: So, as I was saying, I'm asking everybody the same questions and the first one is, can you tell me what you remember about your experience of being told about sudden unexpected death in epilepsy?

P: Yeah, em I think the first time I actually mentioned it, it hadn't been mentioned to me.

I: Oh right, OK.

P: Em...I mentioned it to the paediatrician...

I: Right.

P: ...and he really didn't have a lot of knowledge of it. He said that...he...didn't really, em...he believed it only happened to certain people fought for the name so it was more kind of recognised.

I: Right.

P: He said, em...but he didn't...I dunno, I can't remember

Question 1.

Somewhat hesitant here?
She brought up SUDEP initially, not a professional.

She initially mentioned it to her paediatrician.

Her paediatrician didn't know much about SUDEP, and has an assumption about why it was recognised as an issue for those with epilepsy.

Slight hesitation, her memory of this is patchy, although

Parent initiated SUDEP conversation.

Professional assumptions.

<p>exactly what he said. But he, em believed it was the em...do you know, the SIDS type thing.</p> <p>I: Right, OK.</p> <p>P: And whether they had epilepsy or not it wouldn't have really mattered, so...</p> <p>I: OK.</p> <p>P: Em...so I just never really bothered asking again.</p> <p>I: Em and you said you had asked him about it?</p> <p>P: Yeah, I'd asked him about it when H was really young cos obviously, it's like I had gone through what if this could happen, what if this could happen...</p> <p>I: Mhm.</p> <p>P: ...mebbe he's got this, because he went...he had epilepsy but he went undiagnosed for other syndromes for a <i>long</i> time...</p> <p>I: Right.</p> <p>P: ...and I'm like mebbe it's this because this is lining up with this and that and...</p> <p>I: Yup.</p> <p>P: Em, so I went like a year of Googling everything just to see if I could find out, and em...then I realised you cannae. And I was worrying what if this happens and, do you know, and I wouldn't sleep at night in case anything happened, he's not breathing or whatever.</p> <p>I: Yeah.</p> <p>P: Em, so, but then I thought you know if it's gonna to happen it's gonna happen, we just need to live our life to</p>	<p>she does remember him comparing it to SIDS. <u>Sense of her recounting a difficult conversation?</u> <u>She didn't ask questions about SUDEP as the paediatrician was dismissive?</u></p> <p><u>Sense here is that the paediatrician was dismissive of this being a concern.</u></p> <p>Her response to this conversation was to not ask about SUDEP again. <u>How did she feel about this?</u></p> <p>Sense of her worrying about SUDEP as an event that could happen for her child.</p> <p><u>I wonder what her understanding of SUDEP is.</u> Time frame of diagnosis.</p> <p>She was trying to work out for herself what was happening.</p> <p>To get information she turned to the internet for a year. <u>Sense of seeking knowledge and increased worry.</u></p> <p><u>She couldn't sleep in case something happened. indicates her heightened sense of risk.</u> Doesn't use words related to death.</p> <p><u>She used a strategy of saying it was out of her control to manage her worry.</u></p>	<p>Not encouraged to ask Questions.</p> <p>Perception of risk.</p> <p>Perception of risk.</p> <p>Knowledge. Time frame.</p> <p>Information gathered online. Worry.</p> <p>Perception of risk. Sleep.</p> <p>Lack of control. Focus on here and now.</p>
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<p>the full. So yeah.</p> <p>I: So, you had gone away and had a look at things online, and then found out about SUDEP online.</p> <p>[Recorder switched off due to interruption by participant's dog]</p> <p>I: Right, we're back, OK so you were saying you'd gone away and done some Googling and then actually you spoke to the paediatrician.</p> <p>P: Yeah.</p> <p>I: And he was saying to you that actually this isn't...</p> <p>P: He didn't...</p> <p>I: He didn't really believe it was something that happened. So when you went and spoke to the paediatrician, how did you feel after you'd spoken to him?</p> <p>P: I just felt...mmm well, obviously if he doesn't think it's a concern, it's not really a concern.</p> <p>I: Mhm.</p> <p>P: But at the times when he was very ill, obviously I worried and worried and worried about it. I wouldn't sleep at night, I watched him and things like that...</p> <p>I: Uhuh.</p> <p>P: ...obviously then I was so tired and so exhausted...</p> <p>I: Yeah.</p> <p>P: ...and then obviously having a new born baby as well, into the mix, I thought I can't keep worrying about this because it's going to affect my health so, you know, you just have to live each day. So, what's going to happen is</p>	<p><u>Professional attitude to SUDEP shaped her perception of the risk.</u></p> <p><u>At the time of this conversation her son was really unwell, which may explain her searching online for information.</u> She couldn't sleep and watched him.</p> <p>She was very tired.</p> <p><u>Sense of feeling overwhelmed.</u> She was worrying a lot. Again focusing on idea of living one day at a time. Lack of control over outcome.</p>	<p>Perception of risk.</p> <p>Sleep. Observation of child.</p> <p>Fatigue.</p> <p>Overwhelmed. Rumination. Lack of control.</p>
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<p>going to happen, I mean we nearly lost him quite a few times, so I thought, no, you need to make every day amazing.</p> <p>I: Mhm.</p> <p>P: So...and don't worry about it so I just never. Really. Obviously it's still there in the back of my mind and concerns me, and things like that, and...em but you can't...em if it's going to happen it's going to happen.</p> <p>I: And did you speak to anyone else after you spoke to the paediatrician?</p> <p>P: No. No...and it was never ever mentioned after that.</p> <p>I: Right.</p> <p>P: I think they mebbe they don't really men...I mean they have mentioned it when he started to get better and that they said there's a high risk that he might have another massive seizure because he was in this status for a long time where he just seized constantly. So, em, they were like oh it could happen again blah blah blah and it never. And so the way I thought was they're telling me things like this is because everything else is a bonus then.</p> <p>I: Mhm.</p> <p>P: Like they said that he wouldn't walk and talk and he is walking and talking, and so, but I never actually mentioned it after that.</p> <p>I: And what do you think about that – that they didn't mention it? That you had to bring it up?</p> <p>P: I think that, I can see two sides of it, em maybe if they did mention it there'd be some parents who'd panic every single day, you know. But then if it's not mentioned, you know some people don't know about it obviously. Cos I have done so much research on it, every bit of...like I know</p>	<p>He was so ill, there were times she thought he might die.</p> <p>She was able to stop worrying by focusing on the present. However, she mentions it was still there. Worry / rumination. Lack of control.</p> <p>Did she not mention it due to her experience bringing it up with the paediatrician?</p> <p><i>She seemed to cut of the word mention here.</i> She had another conversation about it due to her son being at a high risk of SUDEP.</p> <p>Her son was having severe seizures. <u>Feeling that she is being dismissive of SUDEP here, but somewhat contradictory – on the one hand it hasn't happened, on the other every day is a bonus – seems she is still holding the possibility of SUDEP in mind.</u></p> <p><u>She then talks about an instance where her son did things that professionals said he wouldn't do. What is her level of trust in them?</u></p> <p>Verbalising she sees two sides to things. She recognises some parents might panic. If SUDEP wasn't mentioned, some people might not find out about it. She's spent a long time looking up information about</p>	<p>Anticipation of death. Focus on the present.</p> <p>Avoidance of worrying thoughts.</p> <p>Lack of control.</p> <p>Perception of risk. Severity of illness.</p> <p>Trust / distrust of medical professionals.</p> <p>Concern for other parents.</p> <p>Lack of knowledge.</p> <p>Parental research.</p>
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<p>about it and it's there forever, you know. But, em... I don't dwell on it constantly, you know. Em, but I do think it needs to be mentioned, because as I say it's never ever been mentioned apart from that time I brought it up to the paediatrician.</p> <p>I: Yeah.</p> <p>P: But the neurologist has never ever mentioned it.</p> <p>I: Yeah, OK that's interesting.</p> <p>P: But I've never brought it up again.</p> <p>I: Right.</p> <p>P: So...</p> <p>I: And did you have other questions you wanted to ask?</p> <p>P: I think I would have mebbe have, but em (pause) I thought, well I'm not going to keep asking. Em...</p> <p>I: Were you given any written information about SUDEP?</p> <p>P: No.</p> <p>I: OK. OK, So it was purely you bringing it up?</p> <p>P: Yeah.</p> <p>I: And then getting that little bit of information.</p> <p>P: Yeah, I think in the early days, em I was at the stage of what if this happens, what if this happens, what if this happens...type of thing, so...em, but now it's just d'you know, he's got epilepsy but it doesn't change him. We just carry on with life you know.</p> <p>I: Mhm. And so thinking about that, you know you happened to ask. What was that like for you?</p>	<p>SUDEP. Now she knows she can't not know. She doesn't think about it all the time. She had to bring up the subject of SUDEP.</p> <p>It wasn't mentioned by the neurologist; <u>does she think it should have been?</u></p> <p>She didn't bring it up again after that initial conversation with the paediatrician.</p> <p><i>Tails off.</i></p> <p>The initial conversation had such an impact questions she wanted to ask, she didn't.</p> <p>She didn't get any written information.</p> <p>In the early days of her son's illness, she was in a state of worry and rumination about what might happen. <i>Hesitations here, use of em.</i> <u>The diagnosis doesn't change who her son is.</u> Repetition of her way of coping by 'getting on with things'.</p>	<p>Parents initiating finding out.</p> <p>Impact of professional opinion.</p> <p>Anticipatory anxiety. Rumination.</p> <p>Coping.</p>
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<p>P: Em, I felt that I had to ask because obviously it was really concerning me. Em, and obviously I wasn't sleeping and things like that – worried about him and checking on him like and if I did fall asleep I had my alarm set for every forty minutes throughout the night. And being a single parent, it was a bit hard, yeah. So em, I thought I <i>need</i> to ask about it just to kind of keep my mind at rest. And I don't know if they mebbe said that just to make me feel not as worried you know, obviously mebbe it's something that happens but they believe it's caused by this and not that...</p> <p>I: Yeah.</p> <p>P: ...but what happened was that people that had had epilepsy fought for it to be recognised and so really it was just that. So I don't know if it was for me to feel better, I don't know.</p> <p>I: What did you think about that explanation?</p> <p>P: It...it...kinds just thought well I'm not going to ask about it again you know because obviously if it's not concerning them, it's not concerning me em and just kind of get on with things. But I do think there should be a kind of way of explaining it. But then obviously, then you might get parents who just totally panic, you know.</p> <p>I: It's a difficult one.</p> <p>P: Yeah.</p> <p>I: So you were mentioning there that you had quite a bit of worry.</p> <p>P: Yeah, oh yeah, I had massive anxiety in the early days.</p> <p>I: And what kinds of things were going through your mind?</p> <p>P: Em, you know, what if I sleep in and he doesn't...cos the morning that em it first happened, I'd woke up and he</p>	<p>She thinks it was really concerning. <i>Use of word obviously twice to emphasise her concern.</i> <i>She was worried. She was checking him during the night, shows the impact of her worry.</i> It was difficult because she is a single parent. <u>She's shouldering all the blame?</u> <i>Emphasis on word need, she has to ask as she is solely responsible? She thought they told her information so she didn't worry.</i></p> <p>Here she goes back to the idea that SUDEP is rare, but that she wasn't sure if this was information told to her to reassure her. <i>She sounds doubtful here, repetition of 'I don't know'.</i></p> <p><u>If it doesn't concern professionals, it shouldn't concern parents?</u></p> <p>Professionals should explain it in a kind way.</p> <p>She was very anxious. Time frame.</p> <p>Hesitation about what could happen if she slept in and what the consequences could be.</p>	<p>Sleep. Worry. Checking child regularly.</p> <p>Reassurance by professionals.</p> <p>Perception of risk.</p> <p>Empathy from professionals.</p> <p>Anxiety. Time frame.</p> <p>Anticipatory anxiety.</p>
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<p>hadn't woken up this morning and I was looking at my watch like, it's a bit late he normally gets up at seven and has his bottle em and when I went over the cot he was unconscious right. And then from that day I struggled to sleep in case, because I thought how long has he been unconscious, do you know what I mean. Eh and things like that. And when he was in the hospital I was like how long had he been unconscious, and obviously it was guilt and stuff, you know.</p> <p>I: Mhm.</p> <p>P: How long had he been lying there, you know? Oh, so it's half nine now, em...and he should have got up at seven. Obviously he'd not woken me up with his cry and I'd just slept on, you know. Em, so obviously I had this guilt and I thought, oh I can't go to sleep again. I had my mum and my auntie and that...like I would have a sleep and then she would have a sleep...</p> <p>I: Right.</p> <p>P: ...and they stayed with me and things like that so I could make sure there was always somebody awake with him throughout the night. Em, so it was hard in the early days.</p> <p>I: How long did you do that for?</p> <p>P: Em...oh for months and months and months. After he came out of hospital, when he was in hospital obviously the nurses were round him and stuff, and he was in hospital for months. But when he came home that was our life for a long time. And then obviously he started to get better and we thought we can...em...cut some of this down as we go along type of thing. And em...(long pause)...</p> <p>I: You mentioned the support from your family, did you talk to them about SUDEP?</p> <p>P: No really, I just...it wasn't something we really talked about eh. Em...obviously we talked about his epilepsy, but</p>	<p>She is remembering an occasion when he had his first seizure and he had had a seizure. From then she had trouble sleeping. <u>Did this and her thoughts about SUDEP heighten her anxiety?</u></p> <p>She felt guilty about sleeping in because she didn't know how long he'd been unconscious for.</p> <p><u>She remembers this event in some detail, including the timings indicating how awful she felt about sleeping in.</u></p> <p><i>She repeats her feeling of guilt about it.</i> <u>She felt so bad, she felt she couldn't go to sleep again. So much so, she got her mum and aunt to help so they could sleep in shifts.</u></p> <p>It was difficult, but there was support from her family in the beginning.</p> <p>She talks about having this worry and sleeping in shifts for a long time, for months. <u>You get a sense that this was the focus of her life.</u></p> <p>This reduced over time as her son got better.</p> <p>She didn't talk to her family about SUDEP.</p>	<p>Anticipatory anxiety.</p> <p>Guilt.</p> <p>Guilt. Sleep.</p> <p>Family support. Difficult. Time frame.</p> <p>Duration of worry.</p> <p>Transition over time.</p>
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<p>there were times where...I mean at one point we were planning his funeral, you know. So...so it was hard. We talked about that, but we didn't like talk about it since or that, you know. So we just kind of got on with things, you know.</p> <p>I: So when you were talking about planning his funeral, was that during a particular period?</p> <p>P: Yeah, when he was on life support. They didn't hold out much hope for him, so em...so em obviously we were thinking about what we would like and that, you know. Em...so...</p> <p>I: That sounds like it was a really difficult time.</p> <p>P: It was a really difficult time, yeah. And I mean...things come back from that...I don't remember a massive amount about it, I was mebbe just in my own wee world, you know.</p> <p>I: Mhm.</p> <p>P: Em, it was really hard. Em...so...but things come into my memory, like em when you see something and you think oh, and then a memory will come back to you from that time. But, yeah. There were bits that my mum could remember that I couldn't remember. Totally distraught.</p> <p>I: Just trying to get on...</p> <p>P: Yeah.</p> <p>I: Which is really difficult isn't it, because when things like that happen we just try and cope the best we can.</p> <p>P: Yeah.</p> <p>I: So you mentioned kind of before you had that chat with the paediatrician about SUDEP, that you'd Googled and you'd looked at information, after you'd had that conversation did you do any more Googling?</p>	<p>She doesn't mention SUDEP here, but perhaps she didn't mention it because her and her family were already worried about her son dying. Their way of coping was to get on with things, use of <i>collective 'we' here</i>.</p> <p>She was facing the prospect of her child dying. <u>She says 'they didn't hold out much hope' and her words become a bit jumbled, indicates emotional content of this for her talking about it even after the event.</u></p> <p><u>The way she describes this is like a response to trauma, she can't remember much and sometimes things come back to her about it. Did she dissociate to cope?</u></p> <p>Sometimes things trigger her memory, but her overwhelming response was being distraught.</p>	<p>Anticipation of death.</p> <p>Getting on with things.</p> <p>Prospect of child dying.</p> <p>Memory.</p> <p>Distraught.</p>
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<p>P: I think I...I think it stemmed off as I'd read so much, as I thought I...every time I looked at these things the prognosis isn't good em...so...I just stopped cos it just puts the fear of death into you if you go onto Google and look at things you know.</p> <p>I: And there's a lot of, sometimes unhelpful, information on the internet...</p> <p>P: Yeah.</p> <p>I: ...did you find things that were particularly difficult to read?</p> <p>P: Em, just mebbe people with the condition and I thought oh H has got this. Em and obviously the prognosis wasn't great and things like that. And so that would worry me about the future and things like that, you know.</p> <p>I: And what were you thinking about the future?</p> <p>P: I was just concerned obviously when it gets to the stage where, like I would worry about...like I still worry about way in the distance like when he's an adult and things like that, when he's an adult and that and I'm not here you know. And em...who's going to look after him, you know. He will probably never be able to live independently you know and things like that, so.</p> <p>I: So you had some information from the internet, were there any other forms of information that you got?</p> <p>P: Yeah, I joined quite a few groups online and things for support and em we had a local mums group of kids who have special needs.</p> <p>I: Oh right.</p> <p>P: Em that I went along to and things so there was a lot of support and, em, H attends some like special needs like</p>	<p>She read a lot of information on SUDEP. She read information where the outcome was poor. This information scared her.</p> <p>Where she had the most worry was information about children with similar difficulties as her son. <u>Epecially those where SUDEP had happened?</u> Concern about the future.</p> <p><u>She is talking about previously worrying and then says she still worries.</u> She is talking about loss of a life her son could have had, he will always be dependent on her and she worries about what will happen if she isn't there in the future.</p> <p>She will always be responsible for him.</p> <p>She looked for support form peers.</p> <p>She sought out support from others and also support for her son.</p>	<p>Online information. Fear.</p> <p>Worry. Poor prognosis. Concern for the future.</p> <p>Worry for child's future. Loss of expected life.</p> <p>Lack of independence. Parental responsibility.</p> <p>Support from peers.</p>
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<p>play schemes and that so there was a lot of support and obviously, em, I the early years he was part of a special needs school and they had different groups and we had a lot of support then and things and obviously I'm still friends with the people in that group at that time.</p> <p>I: It sounds like that was helpful.</p> <p>P: Yeah, it was a massive amount of support. And there was like within that school there was a nurse and obviously anything that you needed at that point, just went over to speak to her and sort it out, you know.</p> <p>I: Did you have contact information for a specialist nurse at all?</p> <p>P: Yeah, I did have an epilepsy nurse as well, yeah.</p> <p>I: And have you spoken much to the epilepsy nurse?</p> <p>P: In the early days, yes, massively although obviously she works out of plan because he was on like ten different medications at that point. Eh and obviously at that time it was hard. I was living with my mum, but she...she was a teacher so she was out at school all day so obviously in the early days it was quite hard as I was on my own, you know. And obviously doing all these medications and things...em, so it was a big shock to the system.</p> <p>I: It sounds like with H being diagnosed and finding out more information, it's had quite an impact on your life.</p> <p>P: Mhm.</p> <p>I: What kind of impact would you say it's had?</p> <p>P: Oh it's totally changed type of thing, because em like the wee mum's group I went to before I felt that I couldn't relate to them because obviously they had these wee healthy babies you know who would go here, there and everywhere you know. Obviously I had to make sure I was home for H's</p>	<p>She made friends via these groups.</p> <p><u>She got a lot of support, uses the word massive.</u> She got support from peers and also via school nurse support, which seems really helpful.</p> <p>He was on 10 different medications.</p> <p>It was difficult living with her mum, but when her mum was out she was on her own.</p> <p><u>It seems like she was worried about the number of medications and having to look after her son on her own, which is understandable.</u></p> <p>She couldn't relate to other mums after her son was diagnosed. They had healthy children, she didn't – a difficult comparison. <u>These kids could go everywhere, he son couldn't?</u></p>	<p>Friendship.</p> <p>Support via school.</p> <p>Medication management.</p> <p>Responsibility.</p> <p>Shock.</p> <p>Couldn't relate to peers anymore.</p> <p>Healthy vs ill.</p>
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<p>medications and things like that and obviously working round that, but we just had to and you know, you get used to it.</p> <p>I: Mhm.</p> <p>P: You know and sometimes I used to say I felt like a robot, you know. I didn't know what, like...I was just kind of in that robot mode, this is what I do now, this is what I do next you know, but. Em...so...yeah.</p> <p>I: And do you think it's limited your ability to do things that you might...</p> <p>P: I think obviously it's...I think in the early days it did. Because he was so ill and sometimes didn't manage to get out the house as much and things if he'd had a few seizures that morning and things. But now, we just, we just get on with it you know. If he has a seizure and goes on the ground...he does, we do what we need to do and give him a wee rest and we're back up again and go and do something else, so you know.</p> <p>I: It sounds like you've kind of adapted?</p> <p>P: Yeah, it just, it fits into everything you know...so.</p> <p>I: So thinking about, we've talked a little bit about you finding out and how that was. Thinking about kind of longer term, do you think that SUDEP and the epilepsy has impacted on your relationship with H?</p> <p>P: I don't think it's really affected it, obviously as I said it did worry me in the early days, like it's still a concern in the back of my mind, but em, you cannot sit there and worry about it all day every day you know. I mean, or you're not going to have a life, you're not going to have a great life for H because you're going to be constantly worried and constantly having to go in and watch him you know. And then he's getting to the age, he's now ten, where he needs, he needs to be more independent and that you know and</p>	<p><u>They had to be at home for medication – sense of feeling restricted.</u> She and her family just had to get used to it.</p> <p>She felt like a robot, on autopilot?</p> <p>She was going through the motions to get through the days.</p> <p>To begin with, she couldn't go out. Time frame.</p> <p>Repetition from earlier about getting on with things.</p> <p><u>She doesn't mention how she feels about this.</u></p> <p><u>She responds initially by mentioning her early worry and that this is still a concern for her.</u> Idea that to function you have to get on with things and can't worry. <u>Worry as something that means you can't function?</u></p> <p><u>She's thinking ahead to the future.</u></p>	<p>Restricted by medication.</p> <p>Getting though the days.</p> <p>Restriction of activity. Time frame.</p> <p>Time frame. Concern.</p> <p>Future independence.</p>
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<p>he's, he's started walking to school and things like that. And he needs to do that you know (laughs). You cannot wrap em in cotton wool forever so...if it happens, it happens you know. And there's nothing that I've done that's caused it you know and em you know...you just cannot dwell on them you know.</p> <p>I: It sounds like you've kinda come to a place where...</p> <p>P: Yeah...</p> <p>I: ...you think, it could happen, but...</p> <p>P: Yeah.</p> <p>I: ...but actually you can't sit and worry about it all the time.</p> <p>P: I mean, cos there's been so many times where we've nearly lost him that I think it <i>could</i> happen.</p> <p>I: Mhm.</p> <p>P: I mean, we could lose him, but we cannot sit every day and think like that. We just have to give him an amazing life. Live life to the full every day...so...</p> <p>I: It's interesting how people respond to those situations...</p> <p>P: Yes.</p> <p>I:...do you think that H has got an understanding of his condition?</p> <p>P: He knows that he has epilepsy, eh, um he knows that he has some needs, but he doesn't let it bother him...really.</p> <p>[Participant's daughter came in at this point and went to use computer with headphones on.]</p> <p>I: Does he ever talk to you about it?</p>	<p>Idea of not wrapping her son in cotton wool. She immediately goes to the idea of something potentially happening if she's not hypervigilant.</p> <p>She is aware of the possibility of something happening, but feels she can't worry all the time.</p> <p>She's had to face the possibility of him dying on a number of occasions.</p> <p>Here she is acknowledging there is a risk, but that she has to focus on what she can do to give her son a good life.</p>	<p>Worry.</p> <p>Facing death.</p> <p>Living for the moment. Giving her son a good life.</p>
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<p>P: Em, he does talk to us, doesn't he. About his epilepsy, yeah. He went through a phase of, you can't get me into trouble, I've got epilepsy. I can't do this, I've got epilepsy! I'm like, yeah you can!</p> <p>I: so he was using it as a little bit of a...</p> <p>P: Yeah.</p> <p>I: ...excuse?</p> <p>P: Oh yeah. I mean there was a time where he played it so much that the school were so worried that they'd send for me every five minutes because he'd say I think I'm having a seizure, then he'd get home and get to relax...but we soon nipped it in the bud, didn't we (all laugh).</p> <p>I: Do you think it's had any impact on your other children?</p> <p>P: I think...yeah, apparently at school she does look after him...</p> <p>I: OK.</p> <p>P: They fight like cat and dog at home, but em at some points we used to take him to breakfast club and she'd take his jacket off for him and he likes everybody to do everything for him and...I mean we nipped that in the bud as well. But she does, she does worry about him when he's not here....yeah you do, don't lie – she knows we're talking about him!</p> <p>I: That's a nice thing, yeah. It means you worry about your brother.</p> <p>P: Mhm.</p> <p>A: He's coming.</p> <p>P: You mean now?</p>	<p>She talks about epilepsy being used by her son as a way of getting out of doing things. <i>Some humour here.</i></p> <p><u>She doesn't let him get away with that.</u></p> <p>This got to a point where school were very concerned.</p> <p><u>She set a boundary here for her son.</u></p> <p>Her daughter looks after her son when they are at school.</p> <p>She set a boundary of getting her son to do things for himself. Her daughter also worries about her son.</p>	<p>Child using epilepsy as a reason not to do things.</p> <p>Impact on siblings.</p> <p>Boundaries. Parenting skills. Siblings.</p>
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<p>I: You can see him? Well, we'll be finished in just a wee minute. Just a couple more questions. So thinking about your experience of being told, or not being told, about SUDEP, what do you think clinicians should tell parents?</p> <p>P: I think it's something that has to be mentioned, I think that obviously if they don't...if the worst happens, then...em...you're gonna be really angry with them for not telling you, you know. But I think it obviously needs to be worked on the way that they, that it's told to people – that it exists.</p> <p>I: And what would you think would be a good way of doing that?</p> <p>P: Em....(long pause)...I'm not really sure what would be a good way of explaining something like that. Em....em...mebbe like...you don't want to frighten everyone you know. But maybe some like information posters or something, because I really haven't seen anything like that before you know. Obviously you see it for the...em...for babies and things like that, but you don't see it really for people with epilepsy. I think people need to be made aware of it but obviously how in a good what that'd be totally....shown you know, because obviously it's a serious issue, so...</p> <p>I: It's difficult isn't it, because like you say it's about providing the information but doing it in a way that doesn't worry people.</p> <p>P: Yeah.</p> <p>I: So I suppose your experience was that you weren't given that information at all...</p> <p>P: Yeah.</p> <p>I: ...so kinda what you're saying is that, just thinking about that quite carefully. That clinicians should <i>tell</i> people and for them to think carefully about what information they give</p>	<p>Question 4</p> <p>SUDEP needs to be mentioned by professionals otherwise parents wouldn't have all the information they might then need to have known.</p> <p>There needs to be a different, empathic, way to tell parents.</p> <p>She struggles to think of how this might be done.</p> <p>It's important not to scare people.</p> <p>Information for different ages.</p> <p><u>Difficulty in presenting what is fundamentally difficult information to parents.</u></p> <p><i>Tails off.</i></p>	<p>Professionals need to be empathic.</p> <p>Sensitivity of information provision. Information posters.</p>
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<p>and wider how they provide information.</p> <p>P: Uhu.</p> <p>I: And do you think that information should come from anyone in particular?</p> <p>P: Em obviously someone with a, someone with a... I don't know, even em if they mebbe had a place on the wards and that, a place to talk to someone and they've got that training and obviously there's people em obviously if their child is very ill, em they're not going to take information in as well you know. So you don't know when the best time is, as obviously when and how and things like that, I really don't have a clue.</p> <p>I: The timing's difficult. For you, what do you think would have been a good, if there is such a thing, a good time?</p> <p>P: I think even if I'd just been told, rather than just finding out on the web which was so worrying and asking about it and not really getting a, a straight answer really.</p> <p>I: Mhm.</p> <p>P: Em...so, em I really don't know. Em as I say the information's the important thing and then people then approach the neurologist and talk about it and get a kind of straight answer you know. Em, if there's a there a risk, em...is there a risk for my child? I mean type of thing, so.</p> <p>I: Mhm. So having it specific to each child?</p> <p>P: Yeah, but obviously you never know, you know so, you wouldn't want to say this will <i>never</i> happen to your child, you know so you don't know.</p> <p>I: And I suppose you know, explaining it in a way that's helpful for each parent?</p> <p>P: Yeah.</p>	<p>Somewhere private to talk about a difficult issue with someone who is trained.</p> <p><u>Recognition that if you are given difficult information, it might be difficult to take it in.</u></p> <p><u>Timing is difficult.</u></p> <p><u>But being told is better than not.</u></p> <p>She didn't have a chance to ask questions.</p> <p><u>It would be important to get information from the neurologist and have a frank discussion.</u></p> <p><u>Bespoke information would be best.</u></p> <p><u>Giving a realistic idea for parents of risk is important.</u></p> <p>Explained to suit the parent.</p>	<p>Privacy when getting information.</p> <p>Timing. Taking in information.</p> <p>Timing of information provision.</p> <p>Parents need to be informed.</p> <p>Bespoke information.</p> <p>Realistic idea of risk.</p> <p>Bespoke.</p>
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<p>I: So overall, what do you think is helpful for clinicians to keep in mind for telling parents?</p> <p>P: Yeah, it has to be said very very sensitively, them things, I think because when you've got a child with a severe illness then it's hard enough and you're going to be worrying enough about everything...em...so they need to find a way of giving this information over sensitively, you know. In a way that we understand, they throw all these medial terms around and things and sometimes you don't have a clue, you know. It sounds more worrying when you do not know, like if they give you a name for something and you don't know about it... it worries you even more. So, I think they need to explain things, you know...</p> <p>I: In understandable language?</p> <p>P: Yeah.</p> <p>I: Yeah, I think that's a really good point.</p> <p>P: And handled sensitively, yeah.</p> <p>I: Yeah. We've gone through all the questions, and I suppose just to round off, is there anything else that you think is important for me to know or anything that you think would be helpful to other parents?</p> <p>P: Yeah, I think that obviously it's a serious issue and obviously it is something that needs to be thought about and eh you need to be knowledgeable about it, but do not let it take over your life because em obviously all the worries and concerns that I had did take over my life for a while when he was very very young, em and you can't live like that you know. You can't be awake 24/7 worrying about it you know, you just have to make every day special. So, yeah...</p> <p>I: That's a good place to stop! So thankyou.</p>	<p>Information needs to be given sensitively.</p> <p>It's difficult enough when a child is ill, and then adding the stress / worry of SUDEP on top.</p> <p>Needs to be understandable, not using jargon or medicalised terms.</p> <p>Information needs to be explained where medical terms are used.</p> <p>It's a serious issue. It needs to be considered carefully by professionals.</p> <p><u>Her worries 'took over'</u></p> <p>You can't worry all the time, need to focus on the present.</p>	<p>Stress of caregiving for an ill child.</p> <p>Understandable information. Lay language.</p> <p>It's a serious issue.</p> <p>Worry.</p> <p>Focus on the present.</p>
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[Recording ends].

APPENDIX O: Empirical Article: Example Theme Generation Table.

Interview 10: Emergent Themes	Themes
<p>Parent initiated SUDEP conversation. Professional assumptions. Not encouraged to ask Questions. Perception of risk. Perception of risk. Knowledge. Time frame. Information gathered online. Worry. Perception of risk. Sleep. Lack of control. Focus on here and now. Perception of risk. Sleep. Observation of child. Fatigue. Overwhelmed. Rumination. Lack of control. Anticipation of death. Focus on the present. Avoidance of worrying thoughts. Lack of control. Perception of risk. Severity of illness. Trust / distrust of medical professionals. Concern for other parents. Lack of knowledge. Parental research. Parents initiating finding out. Impact of professional opinion. Anticipatory anxiety. Rumination. Coping. Sleep. Worry. Checking child regularly. Reassurance by professionals. Perception of risk. Empathy from professionals. Anxiety. Time frame. Anticipatory anxiety. Anticipatory anxiety. Guilt. Guilt. Sleep. Family support. Difficult. Time frame. Duration of worry. Transition over time. Anticipation of death. Getting on with things. Prospect of child dying. Memory. Distraught. Online information. Fear. Worry. Poor prognosis.</p>	<p>Finding Out Parent initiated SUDEP conversation. Parents initiating finding out. Not encouraged to ask Questions.</p> <p>Communication with professionals Professional assumptions. Trust / distrust of medical professionals Impact of professional opinion. Empathy from professionals. Medication management. Professionals need to be empathic. Reassurance by professionals.</p> <p>Perception of risk Perception of risk.</p> <p>Coping Focus on here and now. Avoidance of worrying thoughts. Checking child regularly.</p> <p>Emotional Impact Sleep Fatigue. Overwhelmed. Rumination.</p> <p>Support Family support Couldn't relate to peers anymore.</p> <p>Process / Stages Transition over time</p> <p>Illness & Loss Anticipation of death Prospect of child dying Loss of expected life. Healthy vs ill.</p> <p>Information Seeking Online information. Sensitivity of information provision. Information posters. Privacy when getting information. Timing of information provision. Parents need to be informed. Bespoke information. Realistic idea of risk. Bespoke. Understandable information. Lay language.</p> <p>Role change / Limitations Restriction of activity</p>

<p>Concern for the future. Worry for child's future. Loss of expected life. Lack of independence. Parental responsibility. Support from peers. Friendship. Support via school. Medication management. Responsibility. Shock. Couldn't relate to peers anymore. Healthy vs ill. Restricted by medication. Getting through the days. Restriction of activity. Time frame. Time frame. Concern. Future independence. Worry. Facing death. Living for the moment. Giving her son a good life. Child using epilepsy as a reason not to do things. Impact on siblings. Boundaries. Parenting skills. Siblings. Professionals need to be empathic. Sensitivity of information provision. Information posters. Privacy when getting information. Timing. Taking in information. Timing of information provision. Parents need to be informed. Bespoke information. Realistic idea of risk. Bespoke. Stress of caregiving for an ill child. Understandable information. Lay language. It's a serious issue. Worry. Focus on the present.</p>	
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Appendix P: Empirical Article: Reflective Diary Extracts

Yardley (2000) emphasises that in good quality qualitative research that transparency is important, noting that researchers should make the reader aware of ways in which the researcher's personal experiences, beliefs, theoretical orientations and personal identity may have shaped or influenced the research. Accordingly, I kept a reflective diary during the study from just prior to conducting interviews, throughout transcribing and during coding and analysis. Extracts are included below.

For each interview, I recorded pre- and post-interview reflections, which initially included my initial apprehension in conducting research focussed on children and young people;

Extract 1

I feel nervous today as this is the first interview for my thesis project. This is also the first time I am going to do work connected to children and young people, something that I have been aligned to as part of my doctorate. At this stage I am not really sure about this as all of my experience has been with older adults and adults so it feels quite outside of my comfort zone. To be honest, it all feels a bit overwhelming. I wonder how much of my anxiety will impact on the interview?

In looking at these reflections nearing the end of the project, I am interested to see that my position in relation to the subject changed quickly after completing the first interview;

Extract 2

I feel relieved to have the first interview completed. I was feeling anxious despite being ambivalent about the subject in general, but wanted to do a good job. After the first few minutes, I became really absorbed in what the participant was saying. I remember having a thought during the interview that I actually really lucky to be getting an insight into such a difficult, emotive subject. I was a bit taken by surprise at this, given my initial concern about if I would find it

interesting. I am looking forward to doing the rest of the interviews now and feel I have gained motivation for the project.

Further into interviewing, I was starting to reflect on my role as an interviewer in the context of my role as a trainee clinical psychologist and my previous experience as a therapist:

Extract 3

I found today's interview challenging (interview 8), the participant was very distressed at points during the interview and I wondered at times if I was lapsing into my more familiar role of therapist. I've previously spoken to my clinical tutor about this in supervision, which helped me to be conscious of advice that I am not there to 'fix' problems or to formulate difficulties. I felt very sad for this lady who had had her life turned upside down, and after the interview was over I was relieved to find out that she was on a waiting list for psychological help.

I think on reading this again, that this interview was important in really highlighting to me the emotional impact on this parent of knowing about SUDEP. It made me increasingly aware of the difference in completing an interview for a research project as opposed to conducting a psychological assessment. While there are things in common in each, such as active listening, the roles are distinct and I think over the course of the interviews I became more comfortable with the role of interviewer.

Extract 4

When I was transcribing interview 8 today, I was reminded about how I felt doing this interview and how emotionally challenging it was. With the experience of having done all the interviews in mind, I was aware that a couple of the interviews has much less of an emotional element to them and I am interested to look at this in more detail when I come to coding.

At this point in transcribing, I was aware that overall I had interviewed parents with a range of experiences. This included those who were seeming very matter of fact about it on one hand, and others like P08 who were more emotional. I think that reflecting

on this during transcription increased my motivation to make sure that my research reflected the range of participant's experiences accurately.

Transcription took a lot longer than I had originally anticipated, and I had a dip in motivation once I had completed the interviews. In addition, I was also concerned about starting coding as a novice IPA researcher:

Extract 5

I found myself really concerned about comparing coding with my supervisor today. It all feels a bit overwhelming at the moment as everything seems relevant and I am finding it hard to move away from the transcribed text to emerging themes. However, when we went through the interviews, I was reassured that I had picked up on similar things to my supervisor.

Following coding, I was apprehensive about generating superordinate and subordinate themes. Again, I found it difficult to move from the codes to overarching themes.

Extract 6

I have been making a first attempt at generating superordinate themes today and to be honest, I have found it totally overwhelming. I am finding myself worrying about missing out things and not representing the participant's experiences properly, and feel there is just too much information to be included. I think I have got stuck in a loop of coding and reading the original transcripts over and over.

By using supervision, I was able to discuss my concerns at this stage and this helped in making an initial attempt at generating themes. My notes during this phase of the project focus on how difficult I found this process. My supervisors were very helpful in highlighting that the interpretation is an integral part of the methodology and this necessitates going beyond the data.

After completing a reflective exercise suggested by Smith et al. (2009, pg. 114), I was able to develop an interpretative analysis framework for the data. In discussing this through with my supervisor, I felt more confident in my analysis. because my interpretation was validated by someone experienced in using interpretative phenomenological analysis (IPA). In addition, I felt more able to share my themes with participants:

Extract 7

Today I went to meet with a participant to share my themes. I was nervous beforehand in case the themes didn't make sense to her, or that the way I had linked them together would seem wrong. However, my fears were not realised. Instead, the participant seemed glad of the opportunity to hear about the results and said that it was a relief that some of the things she had talked about were also experienced by other mothers. In particular, the theme about perception of risk seemed to resonate well with her. We discussed this for some time, and I found that this really helped me to reconnect with the purpose of the research after finding the analysis phase so challenging.

The above reflections highlight my anxiety about representing the participant's experiences, while still developing a coherent interpretation. Towards the end of the project, my stance changed to accepting that my interpretation is one possible understanding of a set of complex data and that this is an important feature in qualitative research.

References

- Smith, J., Flower, P. and Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. Sage Publications Ltd., London.
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